From Ideology to Reality: Current Issues in Implementation of Intellectual Disability Policy

Proceedings of the

ROUNDTABLE ON INTELLECTUAL DISABILITY POLICY

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Foreword & Acknowledgments

The policy roundtable was organised as part of a two month visit by Professor Jim Mansell to the School of Social Work and Social Policy at LaTrobe University, as an Institute of Advanced Study Distinguished Fellow. Ideas about the roundtable evolved during discussions about the visit between Jim Mansell, Christine Bigby, Chris Fyffe and Ian Mclean. This small group also took responsibility for its organisation with the generous support of the staff from the Institute for Advanced Study and the School of Social Work and Social Policy. Thanks too are due to the contributions of annecto – the people network and Jewish Care towards the costs of printing the proceedings.

The success of the Roundtable was primarily due however to the 30 invited participants who represented some of the leading policy players, service provider organisations and research students in the field of intellectual disability in Victoria. The group brought a wealth of policy wisdom and experience to the Roundtable together with a willingness to debate the issues and a passionate commitment to furthering quality lifestyles for people with intellectual disabilities. This Roundtable represents the first of what we hope will be an annual event and a continuing collaboration with Professor Jim Mansell, which will provide a forum for discussion as well as a springboard for action in realising the human rights and social inclusion of people with intellectual disabilities.
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INTRODUCTION

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In many respects, services for people with intellectual disabilities in Victoria are at the leading edge, in Australia and in the world. The movement to reform intellectual disability services in the 1980s and 1990s was pursued with vigour and enthusiasm. There was widespread development of community-based services to replace institutions, the growth of a vibrant non-government sector to provide services but also to advocate for service development, and the passing of the Intellectually Disabled Persons’ Services Act (1986) to enshrine new principles and models in law. The best services in Victoria are as good as anything elsewhere.

As a visitor who has been able to spend time with people in services in Victoria as well as elsewhere in Australia, though, there is also a sense of unease. There is a feeling abroad that the early successes are not being sustained, that there is a risk that services may be slipping back. This sense of unease is characterised by several beliefs which seem to be quite widely held among families of people with intellectual disabilities, staff supporting them and managers and leaders both in non-government organisations and in government:

1. **Cost to government is the primary driver of service design**
   
   Increasingly, it seems that government has lost the sense of direction and commitment it had in the past. It now pursues policies that are dominated by desire to limit costs to the public purse, whatever the consequences for people with intellectual disabilities or their families.

2. **Costs to families and disabled people are increasing**
   
   As a consequence of policy focused on limiting costs to government, people with intellectual disabilities and their families are experiencing worse services than they want or need in at least two respects. Services are providing less staff support per person (typically by making the service bigger) and the queue of people waiting for services is growing.

3. **Disability interests compete with each other for favour from government**

   Government’s decision to severely limit resources has occurred at the same time as expectations about the quality of services for all disabled people have increased. Government’s response to this has been to create a competition for resources which pits different service user groups against each other.

4. **Special needs risk being overlooked (de-differentiation) but sound like special pleading**

   Within the emerging framework of general policy on disability, pointing out the special needs of some groups is criticised as evidence of trying to gain special advantage and failing to act collegially. At the same time, a de-differentiated approach does not cater adequately for everyone (for example, many people with profound intellectual disabilities cannot provide a voice with which to participate in decision-making themselves).

5. **Major external threats to quality of life - occupational health and safety, exclusion from benefits of economic growth (‘no more money’) – are not addressed**

   Part of the concern expressed by people involved in supporting individuals with intellectual disabilities is that forces external to the disability service system are damaging it without being effectively countered. The two main examples of this are (i) the unthinking application of draconian health and safety policy in a way that damages disabled people’s interests in order to reduce risk for organisations, and (ii) the failure to argue the case that resources in intellectual disability are well spent and that further investment is justified.

   There is evidence in support of all these concerns. For me, they are symptomatic of an underlying problem. Government owns disability policy in Victoria. It is the largest single provider of services; it pays its staff more and fosters a sense that they are better than the rest. It imposes working practices it has developed to meet the needs of a government agency on everyone else. It makes policy, sometimes with contributions from selected partners. Consultation is a relatively weak influence. More than this, Government defines the assumptions underpinning policy development and the terms of the debate.
This is not how Victoria came to develop leading edge practice. That was the product of a thriving community of ideas and innovation across government and non-government organisations, with close links with advocates and families. What drove this process of development was a partnership between people in many different situations:

- Families and people with intellectual disabilities themselves
- People in government, both involved in services for people with intellectual disabilities and more broadly, included elected politicians
- People employed in services, both in government and non-government sectors
- Academics and other interested supporters

The movement for change was characterised by a clear commitment to a vision and values shared by everyone, and to a ‘can-do’ approach in which more attention was paid to doing the right thing than to following the rules.

That movement for community living which was so influential in the early stages of development is now much weaker. Its forces have been dissipated by the scale of the practical task of providing better services and by the factors identified above. The leadership role has been left to the disability services branch of government. What has happened in recent years is that the context has changed in several important respects:

- Intellectual disability is not now the only area of long-term care in the spotlight. Services for older people and for people with other kinds of disabilities are now seen as inadequate too.
- Intellectual disability services are certainly much better now than they were – so the sense of outrage which fuelled early developments is now weaker.
- As new kinds of services have become more widespread, the argument for them being a special case, exempt from the standard rules in any relevant field, is weakened.
- ‘Economic rationalism’ is now the dominant paradigm in government, involving beliefs that government cannot really achieve very much, that everything touched by government is plagued by waste and inefficiency, and that everything can be best dealt with in a marketplace.
- Governments now focus much more heavily on image than they did; so they feel the need to control demands for resources and attention and to interpret and manage evidence about injustice. Their language is of ‘partnership’ but this is a peculiarly warm and sticky embrace, in which government makes determined efforts to control how the agenda is defined and what options are ruled in or out. The ‘client’ status of service organisations, receiving almost all their funding from government, also helps make this partnership unequal.

In this new context it is probably a mistake to look to government for leadership. Government’s interest is likely to be in managing down expectations and demands, not stoking them up with new passion and vision. The partnership can only be an unequal one.

So if it is not going to be done by government, who is going to do it? The answer is the same people who kicked government into action twenty or thirty years ago – families, their disabled members, service providers and people of goodwill in the wider community. It is time to rebuild the alliance between these groups around the vision of a fair deal for everyone who is disabled.

This round-table is designed to begin this process: to explore issues in disability policy in Victoria. It is focused on intellectual disability policy, though the relationship with wider disability policy is itself the subject of debate and will no doubt form part of the discussion. It is intended to promote dialogue and exploration of the challenges ahead in the expectation that:

- What unites participants is more important than what divides them.
- Participants can acknowledge the validity of different perspectives.
- They can work constructively with these differences (even if they can’t all be resolved).

By rekindling the sense of a movement working towards a shared vision, I believe it will be possible not only to improve services for people with intellectual disabilities but to improve the quality of policy-making itself. I do not think that government can or should be shouldered with the task of defining direction and securing progress alone. If government is to help it will do this by engaging with and facilitating the community in a genuine partnership. Today may be a small continuation to that goal.
SUMMARY OF DISCUSSIONS

Morning Session

Aims, Context And Obstacles To Achieving Better Lives For People With Intellectual Disabilities

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Introduction

The morning session focussed on the aims, context and obstacles to achieving better lives for people with intellectual disabilities. A five minute summary was presented of each of the six papers that took as their themes:

- The vision expressed in current policy and its underlying assumptions
- The meaning of community inclusion
- Need for services and their supply
- Factors supporting or impeding implementation
- Organisational strategies for supporting implementation
- Resources, regulation and risk

These presentations are reproduced full later in this report.

After each set of three papers participants broke into six small groups and discussed a similar set of questions:

- What do we think are the big challenges ahead in these areas?
- What are the risks of carrying on as we are?
- What are the things which divide us?
- What are we not allowed to say?
- Are there any areas of common ground?

Implicit in much of the discussion was an acknowledgement that both opportunity and capacity for open and honest discussion of the issues was a luxury seldom accorded to those present. There was remarkable consistency in the themes that emerged from the discussion which are summarised below. Two major themes ran throughout the sessions – the gap between the vision of the State Plan and what happens in practice for people with intellectual disability and their families; and the complexity of implementing the vision of the State Plan for people with severe intellectual disability. An important feature of the discussions was the tendency to use people with more severe intellectual disability resident in shared supported accommodation or using full time day support services as the reference point. This is quite different from much of the promotional material of the State Plan that tends to use people with milder intellectual or physical disabilities to portray its public image. This was significant as it is the support for this group of people with severe impairments that absorbs the bulk of funding for specialist disability services but which tends not to figure highly when concepts such as choice, inclusion and participation are interpreted.

Nature of the State Plan

Lack of clarity

‘Lots of rhetoric, we haven’t really begun to think about what the State Plan really means’

A unanimous theme was a failure to make the vision of the State Plan accessible and clearly articulate what this means for the everyday practice of frontline staff and the lives of the people they support. The concepts embedded in the Plan’s goals remain at a high level of abstraction. This leaves uncertainty for example, about the application of concepts such as choice, rights, responsibilities, participation and inclusion to people with severe intellectual impairment. Ideas about the type of community being referred to are not made explicit nor is there clarity about the meaning of approaches such as ‘whole of government’ in practice.

The lack of a more grounded exposition of the Plan was perceived to have a range of negative implications. Most importantly, its values and goals are open to misinterpretation by staff, particularly those in direct care for whom there is an insufficiently specific guide to expected actions. As a result staff are not always clear on what is expected or of the criteria against which they will be judged. The lack of clarity was perceived as potentially creating difficulties in working with other sectors in joint projects or to bring about change in their practices. It was suggested that greater clarity would enable clearer identification of the common ground between the disability sector and the mainstream health, education, employment and community sectors, and provide a stronger base for joint working.

Greater clarity about the outcomes sought for people with intellectual disability, the purposes of funding and services were thought to be important in the quest to justify a greater share of government resources. The development of more robust outcome measures is one way to
demonstrate that funds are put to good use. Related to this point is the importance of an evidence base that can set out what is being sought, how to do it and the resources necessary.

No blueprint for action
Related to the lack of clarity was a sense that the State Plan was not really a plan but a vision statement, insufficient on its own, and needing to be complemented by an Implementation Plan setting out the incremental steps required to achieve the vision. Importance was given to the development of mid-level policies and short, medium and long term strategies, which as well as guiding implementation would bring greater clarity to the goals.

An implementation plan should require significant systemic change in all sectors rather than a one off events type approach. The challenge was seen to lie with the collective development of an implementation plan with broad based support which does not flow from a ‘top down’ approach. The process of Plan development would also provide space to consider more openly the complexity and different strategies that could be adopted.

An implementation plan must articulate the change to be achieved in other sectors as well as Disability. Inclusion of these will enables resources to be leveraged by people with intellectual disabilities from other sectors through their use of mainstream facilitates and services, such as health and social housing. This means implementation of disability policy must have an outward focus from specialist disability services to other policy worlds, educating and drawing them into Disability related goals. In that way other sectors will have Disability expectations and can be held accountable for implementation. It was also acknowledge that initially additional specialist resources may be required as a catalyst for developments in other policy sectors. These should however be located within other policy worlds rather than separated from them. Suggestion was made too about the potential of motivating and engaging the private sector in policy implementation, by encouraging it to see people with disabilities as consumers. Essentially, an implementation plan needed to have clearly articulated incremental or mid level policies across multiple policy systems.

Recognition of the evolutionary nature of policy
‘washing away good practice with new ideas’
The discussion picked up on the points made in one of the papers (Bigby 2006) that current disability policy reflected an evolutionary process rather than a revolutionary break with the past. The disadvantages of a continual focus on newness were highlighted, which include a depreciation of what has gone before, and the failure to acknowledge and build on good practice and knowledge that already exists.

Recognition of the Complexity of the Tasks and Difficulty in Working with Difference and Diversity
‘it is rocket science’
A strong theme in the discussion was the ‘need to break the silence about how hard it is to work with people with intellectual disability’ and how complex achieving the vision of the State Plan is likely to be. The high levels of skill, time and energy required to enable meaningful participation and create relationships for people with intellectual disability needed to be more clearly articulated. As well as the training required if care models were to evolve into support.

The shift from a differentiated approach of the past, where separate policy was enacted for people with intellectual disability, had focussed attention on one generic version of disability and inclusion rather than a more nuanced one that took into account difference. Potentially this disguises some of the unique needs of people with intellectual disability or the very different ways in which their needs have to be met. Highlighted was the importance of explicitly acknowledging differences not only between people with intellectual impairment and others with a disability but also within the population of people with intellectual disability. However, in response to Clement’s (2006) paper the importance of the equal rights of people with intellectual disability was strongly reiterated, though they might require different strategies to support the exercise of rights. At the same time however the strengths of a de- differentiated approach in drawing out the issues common to all people with disability were acknowledged.

The very salient point was made that the nature of the task does not lend itself to simple solutions which makes it much more difficult to attract political attention and public interest.

Another complexity alluded to was confronting the reality of the difficulty that people with severe intellectual impairment have in speaking for themselves, and therefore the issues the field confronts in deciding who should speak for them as co producers both in relation to their individual needs but also those of the group as a whole. Should this be other people with intellectual impairments, paid carers, families,
advocates and how is the balance to be achieved?
One resolution of this is reflected in the current composition of the Disability Advisory Council of Victoria, which excludes anyone without personal or family experience of disability. However little is known about the participation of people with intellectual disability in advisory forums or the support they may require, which is likely to be of a different nature to that of people without intellectual impairment.

Restraining Factors of the Current Implementation Approach

‘Recognise and use the strength and potential of non government organisations for strategic delinquency’

The current approach to implementing parts of the State Plan were, critiqued particularly in regard to the nature of funding and contractual arrangements between government and the non government sector. These arrangements were seen as failing to recognise and use all the potential roles of the non government sector, neglecting for example, service and workforce development, campaigning and community development. The strongly program focussed nature of funding does not enable the NGO’s to develop their broader organisational capacity or that of their workforces. In addition it tends to disregard or undervalue things that are not services, which hampers NGO’s in undertaking broader community change initiatives. NGO’s were criticised for not challenging the approach taken by government toward them and not adopting a more questioning approach.

The suggestion was that NGO’s should be regarded as equal partners in negotiating funding with government. But that rather than a partnership between the two sectors, the prescriptive and regulatory approach adopted by government sought to micro manage funded organisations. As a result both government and NGO’s attention was too narrow, overly concerned on specific programs and processes rather than outcomes. This stifled the creativity and flexibility of NGO’s, constraining their ability to experiment with different ways of organising their resources to deliver outcomes. It also meant organisations focussed inward rather than outward towards resources available from the community that could be drawn into their operations. Many participants suggested that NGO’s required much greater flexibility to define their own means of achieving desired outcomes.

However, it was recognised that a less program orientated approach to funding would require government to have confidence in the non government sector. It would also mean a more explicit acceptance that multiple ways are likely to exist to achieve the desired outcomes for people with intellectual disabilities, and that less prescriptive control would promote opportunities to build knowledge about these. It would also require government to develop ways to monitor performance of NGO’s to ensure compliance to policy values and expected outcomes in the absence of regulation and micro management. The breadth of roles played by played by government, that included, policy formulation, funding, regulation, and service delivery were seen as causing confusion and conflicts of interest that impeded policy implementation.

Related to ideas of moving away from a program focus was the notion of ‘deinstitutionalising funding’ by removing the various program silos, and moving towards flexible funding for individuals based on assessment of needs. However, juxtaposed with this was concern alluded to earlier with the need to demonstrate outputs and justify increased funding to disability, which could be hampered by ‘shrinking outputs’, if there was only one funding and one output stream for disability.

Risk aversion

A central theme during the morning which was explored further in the afternoon session was the centrality given by government to the management of risk and avoidance of crisis. This included risks related to reputation, health and safety as well as to quality of life and dignity to organisations, staff and service users. It was suggested that the implementation of the State Plan was too constrained by the need to manage the government’s image which led to the proliferation of activities and events, and reluctance to discuss the extent of unmet need and other difficult issues of implementation. Much of the risk management that occurs at the service delivery level was seen to be driven by occupational health and safety legislation. Suggested was the need for a more critical approach and a greater realisation of the impact of that risk management practices which denied choice and opportunities had on the quality of life for people with intellectual disability.

Nature of the Disability Sector

‘too entrenched in its own patch and interested in defending its own turf’

The disability sector was subject to significant criticism, much of which centred on its divided nature and failure to take a united stance. Despite sharing a broad vision about the lives of people
with disabilities, there were seen to be many competing perspectives and priorities. Families and carers were seen to be in conflict with service providers; children’s needs pitted against those of adults; advocacy groups organised by diagnostic groupings competing with each other, reflecting the divisions among people with disabilities that tended marginalise people with intellectual disabilities with whom other disability groups did not want to be associated. There was a suggestion that the history of institutionalisation had contributed to the problems experienced in the sector.

As well as being divided the sector was criticised as being too precious, having a siege mentality, unable to critique itself, too inward looking, narrow, isolated, not well linked to mainstream services and broader issues. A strong theme was the fear expressed by participants, that workers, particularly those in the non-government sector were afraid to speak out about issues as this might threaten their funding. The importance of strong leadership to implement policy across all sectors by the Disability field was seen as crucial but lacking at the current time.

A key perceived challenge was to develop more cohesion across the Disability sector and thus be better able to advocate for funding and implement policy. This could be achieved by recognising the things common across the sector as well as the differences. The field should consider more clearly working to together on shared interests but providing mutual support around the interest/needs of particular part group within the sector [To some extent the ability to do this has been reflection in the Coalition for Disability Rights Campaign launched in the lead up to the 2007 State election]. It was also important for those outside of government to recognise the political realities that constrained those working in government, and build a critical and vocal voice to challenge government.

Learning from action by larger and more powerful sectors that had taken action to develop research agenda’s and leadership was suggested. Although it was noted leadership initiatives are occurring in the Disability sector and various organisations have been catalysts for agenda setting through conferences and strategic use of overseas speakers.

Impact of a devalued field
The value accorded to people with an intellectual disability in the community is low and reflected in the wages and status of the direct care workforce. A core theme was the importance of developing the capacity of the disability workforce particularly in direct care. This was seen to be hampered by the recent changes to industrial relations that are likely to mean greater casualisation and the low value placed on work in this sector by the community which discourages people working in this field. The capacity of direct care workforce was perceived to be low, and requiring strong leadership to effect value shift to understand and put into action state plan visions.

Lack of Public Interest and Political Power
‘they don’t have the same expectations as us’
‘it’s not the community who is leading the call for change they don’t really care’

Public interest in disability policy was seen as important both in terms of the building community inclusion for individuals but also in acting as a lever for attracting more resources to implement policy. However, a strong sense emerged that the ‘general public’ did not have a strong interest or commitment to the policy directions and that Disability issues could muster little real political support. The challenge was perceived then as both educating the general public about the issues, and in gaining their support. The recent TV advertisement was discussed as one of the means by which that organisation was doing community education. The importance too of professionals modelling inclusion and participation of people with intellectual disability in their own lives and communities was highlighted.

Consideration was given to ways of gaining greater political influence and a more powerful voice in government. The approach adopted by People Power of seeking direct political representation was one strategy, and others included broad campaigns such as the Coalition for Disability Rights, that sought media attention as well as targeting individual politicians. One of the difficulties was getting Disability issues on the political agenda, which only seemed to occur when major negative incidents such as the Kew Fire occurred.

Seeking alliance with other marginalised and disadvantaged groups was seen to be an important strategy, especially to tackle the bigger structural issues such as poverty, and social exclusion.

Extent of Unmet Need
The gap between demand and supply of specialist disability support services such as day and accommodation support is a significant obstacle in policy implementation. Unmet demand, is in fact much larger than waiting list figures portray if the ‘hidden’ elephant of unpaid and informal care by family members were to be removed.
and young people and adults with disabilities to be supported to live ‘normal lives’ away from the parental home. It was suggested that many families are on the brink of disaster, particularly where caring is done by middle aged and older parental carers or parents of young people with autism or multiple disabilities.

**Ways of Going Forward**

Implicit in the discussion of challenges outlined above were ideas about ways forward, particularly the need for a more strategic implementation plan, more interpretation of the meaning of the State Plan goals for people with severe intellectual disability and a less programmatic, restrictive and regulatory approach to implementation and in the relationships between the government and the non government sector.

The importance of joint working between the Disability and other sectors both in service delivery but broader systematic change was a strong theme. It was recognised that other government departments and local government needed the support and expertise of the disability sector as they had little expertise in either understanding or implementing the policy directions. Linkages at local level between disability organisations were also seen as important in tackling the disconnections in people’s lives that often resulted from fragmented or program based funding models. Creating better links between government and the non government sector and university researchers was seen as an important way to leveraging research funds but also in making key connections between research and practice and developing a firm evidence for implementation.

**Afternoon Session**

**Jim Mansell**

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**Introduction**

The afternoon session began with a reflection on the morning’s discussions. Jim Mansell summarised the position by saying that there was wide agreement on the nature of the problems facing services for people with intellectual disabilities (and disabled people more generally). People knew what the problems were, but they seemed to feel paralysed by the complexity of the task, the power of negative forces and a feeling of censorship. This led to a sense of an enormous amount of wasted effort, anxiety and grief.

Against this background, there was also a sense of shared responsibility and commitment in the group and a feeling that there was some opportunity to move forward. The task was therefore to find ways of making progress while accommodating differences in perspective and approach.

Looking at the notes of the discussions in the morning, six topics appeared as areas in which it might be possible to make progress:

- Defining a ‘way-point scenario’; articulating what it would be like in 2011, especially for people with profound intellectual impairment, as the State Disability Plan unfolds.
- What would be a single big message to the public and government?
- What middle-level policies will be needed to bridge vision and practice?
- Talking to Workcover and the Occupational Health and Safety Commission about improving the balance between protecting organizations, employees and the people they serve.
- How can government, in the form of the Department of Human Services, get kudos from facilitation rather than direction?
- What alliances need to be built – within intellectual disability, within the entire field of disability, within all social policy? How can they be built and strengthened?

Each of these formed the subject for discussion by a small group.

**Defining A ‘Way-Point Scenario’**

The existing State Plan is aspirational – that is, it sets out values and broad goals without any underpinning resource allocation framework, timetable or arrangements for delivery or monitoring. Most existing information sources confound people with intellectual disabilities with older people with cognitive impairments (eg Alzheimer’s Disease) and some others (eg people with acquired brain injury). This makes it very difficult to work out what is happening to people with intellectual disabilities and their families.

The group was clear that another ‘vision’ document was not needed – the vision in the State Plan is good. What is needed is:

- Measurement of need, both in terms of numbers of people and the quality of their lives. This needs to include population-based estimates so that, for example, the effect of
ageing of families caring for disabled people at home is understood and predicted. Quality measures need to look at all aspects of a person’s life, not just those which are the focus of a particular program or organisation, so that interdependencies can be properly understood.

- Measurement of progress towards meeting need. This needs to include measures of the amount of service provided but also the range of options (so for example ensuring that there are services providing housing with support that can meet the needs of people with challenging behaviour or other complex needs) and the quality of the services as experienced by the people using them and their families.

One way of approaching this task would be to construct a ‘way-point scenario’; a concrete description of the situation of people with intellectual disabilities and their families halfway through the implementation of the State Plan. This would need to include a population-level element – how many people would there be, how many services of different kinds – based on existing trends and the proposals in the plan. It would also need to include some accounts of how individuals in different kinds of situations would be dealt with, to illuminate the processes involved and to flesh out the way in which services would need to work.

What Would Be A Single Big Message To The Public And Government?
One of the issues identified earlier during the Roundtable was the absence of a simple, clear campaigning focus in intellectual disability. Participants noted how single issues – such as the recent campaign to get disabled adults out of nursing homes – were able to generate attention, motivation and action.

The group thought that such a message should appeal to the common experience of everyone and so should take a human rights perspective rather than representing people with intellectual disabilities as different and deserving because of that. It should also cover as many areas of life as possible – housing, employment, health, learning and transport. The key issue was identified as people with intellectual disabilities waiting for the promises made in policy to be delivered – waiting for housing, waiting for support to have a good quality of life, waiting for jobs and so on.

The single big message the group identified was that ‘Nobody should have to wait for a life.’

What Middle-Level Policies Will Be Needed To Bridge Vision And Practice?
This group began by confronting what they saw as a great lack of policy. They felt that there was nothing to translate the vision of the state plan into practical reality on the ground, so that services developed and operated in a relatively ad hoc way, reacting to circumstances rather than shaping them.

Some of the instances offered of the kind of policies needed were expressions of principle: for example, that no-one receiving individualised funding should be placed in a segregated day service, or that no more segregated day centres should be built, or that people should be enabled to grow old in their home (‘ageing in place’) rather than be moved to somewhere else. These were primarily focused on protecting the values embedded in the state plan. Some of them focused on user experience but others concerned staff – so, for example, there was concern about resisting the drift towards casualisation of work and the disparity of pay and conditions between government and non-government organisations.

Others examples focused on planning: for example, that individualised planning needed to be complemented by population-level planning to ensure that a sufficiently wide range of choices was available and that barriers were addressed at a systemic level rather than requiring every individual to fight their own battles. There was concern that action plans, where they existed, were not monitored or reviewed.

Talking To Workcover And The Occupational Health And Safety Commission About Improving The Balance Between Protecting Organizations, Employees And The People They Serve
The group identified a range of problems that needed to be addressed in the interaction between Workcover, occupational health and safety and service provision. These included:

- Lack of recognition of risks to service users’ quality of life of applying rules
- Lack of recognition that services delivered in people’s homes not factories or institutions
- Risk-averse application of rules
- Antagonistic culture making staff feel oppressed and fearful

Members of the group had had some success where they had paid particular attention to working with OHS staff to cultivate a good working relationship and one group had supported service
users to challenge poor decisions. This led on to a discussion about how best to engage with these regulators which developed two main themes. First, it was suggested that agencies should try to actively engage with the regulators locally, developing as good a working relationship as possible and trying to influence the interpretation and application of rules by individuals. One way of doing this might be to develop jointly produced guidance notes covering common topics and setting out a mutually agreed statement of best practice.

However, it was recognised that local engagement would not be enough and that a systemic response was also required. This would need to have a number of components:

• Co-ordination across non-government organisations so that the sector was seen as a unified voice supporting a consistent message

• Involvement of service users and families and of advocacy organisations so that the issues were seen as about achieving good quality of life for people with intellectual disabilities rather than about services trying to escape their responsibilities

• Dialogue with trade unions to try to enlist their support for a more balanced approach to achieving safe practice for workers without damaging user quality of life. It was pointed out that some union members would have disabled relatives and would have first-hand experience of the problems caused.

• Engagement with the policy-making bodies running Workcover and occupational health and safety to tell them about the bad effects of their policies and to try to open a dialogue about ameliorating them

• Parallel engagement with politicians to try to shape new or reshape existing legislative frameworks. It was recognised that the Department of Human Services might have a valuable role here in briefing and informing about the unintended consequences of regulation.

How Can Government, In The Form Of The Department Of Human Services, Get Kudos From Facilitation Rather Than Direction?

Services in Victoria are provided both by non-government organisations and by government itself, which is also responsible for policy, funding and strategic planning. Discussion had earlier identified that government’s model for this relationship seemed to be ‘command and control’, in which the Department of Human Services expected to dictate the terms on which services would be provided by non-government organisations. Non-government organisations wanted a sense of partnership. For them the problem was compounded by the extent to which government expected them to adopt the same administrative procedures as it adopted in its service provision role (though not the same pay nor the same investment in management and leadership).

The group’s analysis of this position was that it wasn’t appropriate to blame government: that the present arrangements reflected the pattern of incentives and disincentives within which the Department of Human Services has to work. The first task is therefore to understand those forces. People were clear that the major forces were to contain expenditure and therefore to (i) deny the extent of need, (ii) exaggerate the potential for informal care or ‘community capacity,’ (iii) emphasise ‘efficiency’ in terms of cost containment over effectiveness in terms of quality, and (iv) weaken criticism. In addition, the group identified a problem in the political context: the political advantage of representing every event, good or bad, as new and therefore of failing to maintain a strategic sense of direction that sustained the vision and values of good services for people with intellectual disabilities.

Changing the Department of Human Services’ role to facilitation would therefore require strengthening their position in response to pressure to focus on cost containment at the expense of quality and availability of services. Thus the group were clear that they would need to build an alliance with the Department. This would have to help the Department represent good work in a way that met the demands from elsewhere in government, or substituted other achievements for them, or effectively rebutted them. This would also require a thriving lobby external to government which could help define the incentives around political decision-making across government.

What Alliances Need To Be Built – Within Intellectual Disability, Within The Entire Field Of Disability, Within All Social Policy? How Can They Be Built And Strengthened?

The group discussing alliances first focused on the purpose of alliances and argued that particular campaigns would require mobilising a coalition of interests focused on that particular issue. This implies (i) a loose network of parties sharing an interest in the movement for equal rights for disabled people and (ii) mechanisms for drawing people together to form campaign groups. The wider network would be characterised by a shared language and set of meanings about discrimination against social minorities sufficient for people to
identify that they were part of the same cause without requiring everyone to take a position on every issue. For example, it would be important that campaigners for social security reform thought about the impact of change on disabled people and sought them out to develop a shared position; or that people campaigning for better services for people with intellectual disabilities did so without appearing to undermine the case for reform of mental health services.

The existence of a wider network and some campaign groups within implies a certain level of interaction between the members – not necessarily very intense or time-consuming, but sufficient to identify potential issues of common concern and opportunities to joint work.

The group recognised two difficulties in approaching this task. First, how to involve people with intellectual disabilities themselves in the process in a way which was meaningful and not tokenistic. Secondly, how to build cooperation between organisations many of whom were in competition with each other for resources or prestige. This applied for example to service-providing non-government organisations, to lobby groups and to universities. Building an effective alliance would take time because it depended on growing trust between partners to the point where they recognise that their own interests are better served by being part of an effective moment for change than by occasionally having specially favoured status with government.

CONCLUSION

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The roundtable and this report are not an end in themselves. They are the beginning of a process in which stakeholders make the space to talk to each other about their hopes and fears for the future.

These early discussions are likely to take the form of ‘confidence-building’ meetings, the primary purpose of which is to build trust between members that difficult issues can be discussed and that different points of view can be accommodated within the overall framework of a movement to improve services for people with intellectual disabilities.

However it is also likely that some areas identified by participants can form the focus for practical work. For example, the problem of the mismatch between health and safety regulations and quality of life concerns was widely shared and the roundtable included people who had already begun to take action in various ways to address it. Similarly, the production of a way-point scenario predicting the state of services in Victoria in 2011 would be useful and does not threaten any participant’s interests.
The Victorian Government’s vision for the future is that:

By 2012, Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria’.

(State Government of Victoria 2002, p.5)

Introduction

Any professional who has worked in services for people with intellectual disabilities for any length of time will be able to list the formal ‘theories’, frameworks and models that have influenced their practice. Some of the key ideas that have had an impact on my thinking are Normalisation (Wolfensberger 1972); Ordinary Life (King’s Fund 1980); Social Role Valorisation (SRV) (Wolfensberger 1983); PASSING (Wolfensberger & Thomas 1983); the Five Accomplishments (O’Brien 1987) and the social model of disability (see Oliver 1990). These ideas are usually reflected in the ways that services publicly describe their aims.

Human service organisations have a number of other ways of clarifying and communicating their intentions to employees, service-users and other interested parties. In Victoria the Department of Human Services (DHS) proclaims its vision, the Disability Services Division publicises its mission, declares its core values, lists service standards, and launches the State Disability Plan with its guiding principles, goals, and priority strategies (Appendix A). As Emerson, Hastings & McGill (1994) observed, ‘It nowadays appears to be accepted as something of a truism that...a ‘value base’ underpins the very existence of welfare services and exerts a pervasive and powerful influence upon their everyday practice’ (p.209).

The need to define and conceptualise an organisation’s core ideas has had a considerable influence on management studies and there remains an enduring conviction that organisations need to clarify their value system and then instil it throughout the organisation (Alvesson 2002; Martin 2002). Table 1 lists key concepts in the Victorian State Disability Plan that might be considered as guiding ‘values’. If an organisation is to achieve its goals then these values ought to be linked to supporting policies, strategies, techniques and employee behaviour (Cunningham 1984).

Emerson et al. (1994) also made the point that, ‘The assumptions that organizational values exert a powerful influence over service quality, or that organizational performance may be effectively improved through changing the attitudes of staff, have received little critical scrutiny’ (p.209-10).

<table>
<thead>
<tr>
<th>Table 1. Guiding ‘values’ in the Victorian State Disability Plan</th>
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</thead>
</table>
| The table lists each ‘value’ and the number of times the word or a variant of it appears in the plan.

<table>
<thead>
<tr>
<th>Value</th>
<th>Count</th>
<th>Value</th>
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</tr>
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<tbody>
<tr>
<td>Accessible</td>
<td>59</td>
<td>Equality</td>
<td>10</td>
</tr>
<tr>
<td>Advocacy</td>
<td>12</td>
<td>Outcomes</td>
<td>10</td>
</tr>
<tr>
<td>Choice</td>
<td>22</td>
<td>Participation</td>
<td>29</td>
</tr>
<tr>
<td>Citizenship</td>
<td>12</td>
<td>People</td>
<td>231</td>
</tr>
<tr>
<td>Collaboration</td>
<td>2</td>
<td>Protection</td>
<td>10</td>
</tr>
<tr>
<td>Commitment</td>
<td>18</td>
<td>Quality</td>
<td>16</td>
</tr>
<tr>
<td>Community</td>
<td>151</td>
<td>Respect</td>
<td>9</td>
</tr>
<tr>
<td>Consultation</td>
<td>7</td>
<td>Rights</td>
<td>25</td>
</tr>
<tr>
<td>Culture</td>
<td>16</td>
<td>Risk</td>
<td>3</td>
</tr>
<tr>
<td>Diversity</td>
<td>7</td>
<td>Support</td>
<td>146</td>
</tr>
<tr>
<td>Empowerment</td>
<td>1</td>
<td>Transparent</td>
<td>3</td>
</tr>
<tr>
<td>Enabling</td>
<td>21</td>
<td>Valued</td>
<td>13</td>
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My aim in this paper is to demonstrate the need to interpret and question the Government’s vision for disabled people, in order to highlight the importance of clarifying the assumptions underpinning specific values, and test out their applicability to the range of circumstances and people covered by the State Disability Plan. More specifically I address the relevance of the Government’s broad vision to the particular circumstances of people with profound intellectual impairment in four areas, building inclusive communities, risk, participation in ordinary living, and choice.

Both Alvesson (2002) and Martin (2002) make the point that that the relationship between an organisation’s vision and what people actually ‘do’ is ambiguous and that there is a need to demonstrate that the ideals permeate cultural patterns. In particular I draw upon 12 months experience of working as a member of the Making Life Good in the Community research project, where I have spent time watching how people with intellectual disabilities are supported in their homes.

I explore some of the ways in which the gap between the vision and what I have observed seems particularly acute. Rather than being able to resolve these issues all I can do is point to their potential importance to managers and practitioners. I offer my views in keeping with the spirit of the roundtable discussion, which is a means to promote understanding.

Building Inclusive Communities

As far as some ‘values’ are concerned it would appear that human service organisations have tried to disconnect themselves from ‘disagreeable’ values in the wider society, which Clegg (2003) calls ‘separatism’. This treats organisations as ‘closed’ systems as if they are immune from environmental pressures (Morgan 1986). Yet organisations are ‘open’ to the environment in which they exist and must therefore address what is happening in the world beyond their immediate boundaries. Suggesting that human services are closed to the environment in the context of discussing attempts to build inclusive communities is a paradox as there have been numerous initiatives that have sought to tap into natural rather than service-based supports.

Harrison (1994) distinguishes between the task and general environments. It is obvious that the general environment contains some hostile ways of understanding disability, which can result in extremely unpleasant experiences for disabled people and the people who support them. Although societies are not homogenous there are ways of thinking about impairment and perceiving people with intellectual disabilities that are shared by a large number of people. The perceptions of people with intellectual disabilities as sick, subhuman, pitiable, a burden, and a menace have been well documented and discussed (Wolfensberger 1975). These ways of thinking about intellectual disability have an influence on our thoughts and feelings through the transmission of social values and social norms (Thompson 1993). This is often conceptualised as the influence of ‘society’.

In my lifetime there have been various shifts, not only in how we understand ‘disability’, but also in how we are allowed to speak about it. This has gone through periods of relative secrecy and openness (see Søkersdal 1997). By today’s standards, the words some authors used when writing about people with intellectual disabilities seem brutal. This view was put forward by Edgerton (1967) in his classic study, The Cloak of Competence.

‘The label of mental retardation not only serves as a humiliating, frustrating, and discrediting stigma in the conduct of one’s life in the community, but it also serves to lower one’s self-esteem to such a nadir of worthlessness that the life of a person so labeled is scarcely worth living’.

(p.145)

Given such views it would not be surprising if there has been a separatist mentality and a reasonable response might be to reframe how we understand impairment and add value to the lives of disabled people. People have promoted a ‘People First’ identity and the use of ‘people first language’ as a means of emphasising our common humanity in preference to terms like ‘the mentally retarded’, which had come to be seen as demeaning, oppressive, and essentialising the way in which we thought about people with the ‘mental retardation’ label (see Snow 2005, for example).

At the level of public policy, organisational rhetoric and service ideology we have tried to ‘flag’ certain values as a means to get people to reprioritise their own. This may influence how some professionals think and act in relation to service-users, especially as services have committed substantial resources to orienting staff to the ideological ‘foundations’ of service provision (Emerson et al., 1994), but it is much less likely to work for members of the public.

Clegg (2003) suggests that the relative isolation of the intellectual disability field means that engaging with concepts developed elsewhere may be slow. This may account for the ambiguous and less overt influence of the social model of disability on people with intellectual disabilities and the formal and informal networks that support them.
For all the positive shifts in attitudes towards disabled people that have been documented, it could still be possible that the views publicly expressed by Edgerton are held more silently by the non-disabled public, and the lives of people with profound intellectual disabilities are still viewed as scarcely worth living. This ‘culture of silence’ seems even more pronounced within services themselves. As a consequence we have moved to a period where many people who work with people with intellectual disabilities are not able to be honest about our own feelings about profound impairment. Sætersdal (1997) argues that the trend to accentuate the positive aspects of disabled people’s lives, to the exclusion of any negative thoughts or perceptions has created an idealised and romanticised climate.

The idealising rhetoric creates an inaccurate picture that has little relationship to the experiences of many staff and family members directly supporting people with profound intellectual disabilities.

This seems particularly true in relation to the State Disability Plan’s goal of Building Inclusive Communities, where the aspiration is for people with a disability to participate fully, equally, socially, economically, culturally, politically and spiritually in an accessible, caring, inclusive, safe, stronger, and welcoming community (State Government of Victoria 2002). If I were to use a single phrase to capture my view of the non-disabled population’s relationship with people with intellectual disabilities it would be that ‘we tolerate them’. The worst stories that are told by staff are experiences of isolation, rejection, hostility, and avoidance. Clegg (2003) suggests that the work environment is poorly designed to identify or work with the emotional distress or negative feelings that arise from ‘care’ work.

This ‘reality’ of the general environment seems more authentically captured in Nick Hornby’s (2005) recent novel A Long Way Down. In the book four strangers meet by chance on the roof of a building on New Year’s Eve, where they have all gone to kill themselves. One of the four, Maureen, has a son who has a profound impairment. Sætersdal (1997) argues that many people may refuse. It may be the case that profound intellectual impairment may never be the type of diversity that is embraced or celebrated by society. Are there any advantages in considering this unwelcome possibility?

Although the rhetoric of ‘celebrating diversity’ is intended to be attractive so that it makes a favourable impression on people’s hearts and minds, the everyday experiences encountered by family members and frontline staff means that for some of them it is devoid of the qualities its authors ‘apparently’ think or hope it possesses.

Reinders (2000) argued that a focus on rights and ensuing legislation has created massive change for people with intellectual disability, but added that legislation can only open doors. What happens when people with intellectual disability walk through those doors requires social change.

The State Disability Plan acknowledges that, ‘Making the Victorian Government’s vision a reality involves changing the way that Victorians think about disability’ (p.11) and that this is a ‘challenge…for the community as a whole’ (p.1). A ‘challenge’ in this context is an invitation that many people may refuse. It may be the case that profound intellectual impairment may never be the type of diversity that is embraced or celebrated by society. Are there any advantages in considering this unwelcome possibility?

Furedi (2004) makes some challenging remarks about social inclusion policies. He writes that, ‘Although the concept of social inclusion is vague, and used to refer to a wide variety of problems, its central focus is to establish a series of linkages between formal institutions and the excluded’ (p.129). As such the Government’s plan to build inclusive communities attempts to shape and control public attitudes towards...
disabled people. He makes the important point that the policies of social inclusion have not been a response to popular demand. There have been no mass demonstrations of non-disabled people demanding that disabled people have access to sports centres, cinemas, cafés or supermarkets. The social gains made by people with intellectual disabilities have resulted more from the efforts of the broader disability movement and advocates rather than their own efforts. I agree with Reinders (2000) that when it comes to people with profound intellectual impairment they are completely dependent on the good will of their ‘moral friends’.

The aspiration of building communities in which disabled people are included goes beyond links with formal institutions to include the expansion of service-users’ informal personal relationships (O’Brien 1987). Furedi (2004) points out that this social engineering project will require the penetration of official institutions into people’s private lives, what he terms, ‘the colonization of people’s informal lives’. As things stand at the moment there is unlikely to be a public outcry from non-disabled citizens if they do not have a close relationship with a person with intellectual disabilities6.

The project to build inclusive communities unfortunately comes up against both individual assumptions about impairment and the surrounding world’s dominant social norms and values. We may not like what we see when we step outside into the harsh world but would it be better to more fully acknowledge this important dimension in the lives of those who support people with profound impairment and the public who encounter them? I am intrigued by Clegg’s (2003) suggestion that it may be fruitful to focus on the difficulties non-disabled people experience when they first encounter somebody with significant impairment(s).

‘When first meeting an adult with intellectual disability you do not know whether they will speak to you and, if not, whether their silence indicates shyness or inability. Some speak with such poor articulation that you cannot understand; or the omission of a crucial piece of information means you understand the words but not their meaning. You may find it hard to look at the person because of unusual features. The person may be warm if somewhat over-friendly as they hug you; equally, they may be suspicious, distressed or rejecting. Small wonder that many find this interactional space disconcerting.’ (p.128-9)

As well as an intellectual impairment, people may have a secondary impairment such as blindness, deafness, physical impairment or epilepsy. ‘Other difficulties or behaviours include incontinence, movement disorders, self-harm or assaults on others. The person may also have socially disconcerting features: dysmorphic faces, baldness, drooling, stereotyped behaviours, or they may make strange noises’ (Clegg 2006, p.127).

It is easy for those of us who have experience of disabled people to take the moral high ground and use our own acceptance of disabled people as a point of principle in order to distinguish ourselves from the prejudiced masses. According to Clegg (2006) the growth of tolerance and acceptance will not happen by condemning or ignoring people who react ‘negatively’ to people who appear to be ‘a bit too different’.

**Risk**

With regard to other values, we might suggest that the human service organisations have been too porous, when it might have been better to have been more impermeable. These are values related to perceptions of ‘risk’.

Services for people with intellectual disability have had an ambivalent relationship to risk. In an oft-quoted article, Perske (1972) made the case for making sure that people with intellectual disabilities were exposed to the benefits of ordinary risk-taking. Some commentators now hold the view that the preoccupation with risk has become so extreme that service-users’ competing rights are being severely compromised to their detriment (see Sykes 2005). Too much pressure from the external environment to act in a particular fashion, whether perceived or real, can cause an organisation to make internal changes that upsets its internal balance so that the health of the organisation suffers (Morgan 1986).

Although we must be cautious of over-emphasising the impact of a vision statement or overstating the impact that one organisation can have on another, the vision and mission statements of the Victorian Workcover Authority point to an important environmental pressure.

‘Our Vision: Workplaces free from risk, injury and disease

Our Mission: To work with all Victorians to progressively reduce the incidence, severity and cost to the community of work-related injury and disease’

(Victorian Workcover Authority 2005, unpaginated).

If we accept Perske’s (1972) arguments about the benefits of ‘normal’ risk taking and the ‘dehumanizing indignity in safety’ (p.200) then a workplace free from risk is not in the interests of either service-users or the employees that support them.
Although public agencies and service organisations are particularly susceptible to pressures from external regulatory and certifying bodies they do not have to passively adapt to the demands and pressures coming from them (Harrison 1994). An organisation like the Victorian Workcover Authority may have a stake in DHS and other human service agencies but it is possible to influence its operations.

An organisation that closes itself off from the environment is as much in error as one that ‘unconsciously’ responds to external pressures. Members of an organisation have an active role in determining its future and key decision-makers have a role in both understanding the environmental conditions facing an organisation and managing its external relationships.

**Participation In Ordinary Living**

Over the last year some of the practices that I have observed have been far removed what I understand to be good practice. For those of us who have worked in human services for a long time we have become ‘certain’ that there is a best way to deliver services. Schwartz (1997) captures this nicely by suggesting that some ideas are, ‘so deeply ingrained in current shared perception and thought that the ‘rightness’ of [them] is as sure as the ground beneath one’s feet’ (p.8). For me this seems particularly true of the notion of ‘participation in ordinary living’.

The view that services should aspire to promote patterns of ordinary living for all people with intellectual disabilities has been well articulated in the literature. Community-based residential services use ‘ordinary’ housing in order to promote ‘ordinary patterns of living’ for the people who live in them. This ‘ordinary living’ includes the extent to which people spend their time engaged in social, personal, leisure, and household activities, which is understood to be a significant feature of their quality of life (Felce & Perry 1995).

Felce and Perry (1995) argue that the driving force for the engagement in these activities is, ‘the desire to take responsibility for the conduct of one’s own daily life and to learn and be supported to do domestic chores such as cooking and cleaning’ (p.800). This argument, rooted in the principle of self-determination, has been repeatedly made by articulate self-advocates.

This is the case, irrespective of a service-user’s degree of intellectual impairment. For example, the principle that residents should learn and be supported to do domestic chores should be constant across all supported accommodation, but what should vary between settings and between people is the level of assistance given by employees so that residents can participate successfully (Jones et al. 2001).

The aim of participation for people with more profound and severe intellectual impairments must be clarified, since we must acknowledge that their ability to engage in many tasks without the help of others is limited. For people with profound impairments the role of staff is to make opportunities possible for residents to engage in activities and give them the support necessary to play a part (Felce 1998). Thus, participation is possible for anyone.

It has become clear from our discussions with the staff groups that some employees do not see participation as straightforward, achievable or a high priority for the residents with profound and severe impairments that they are working with. We have worked with people who are just as ‘certain’ that there are other priorities in delivering services, which are driven by different values.

This was noticeably evident when people were supporting individuals with profound impairments and where health issues were a prime consideration. The house supervisor spoke clearly about her priorities:

‘We do the best we can, one step at a time. First and foremost in the house the priority is client care. Recreation and other things come along. Client care is our priority. If there is spare time you can go for involvement. People should be fit, clean, and comfortable. The other things come after that.’

(FT/TG/280206)

Although it might be this individual worker’s values that influence his work practice, there are any number of organisational documents that people might draw upon to support the priorities apparent in the quotation. The Department’s own mission statement is, ‘To enhance and protect the health and wellbeing of all Victorians, emphasising vulnerable groups and those most in need’ (DHS, 2005, p.2).

The Department’s writing on Duty of Care underlines the vulnerability of service-users. ‘Most of the Department’s clients are vulnerable in some way because of their age, state of health, social circumstances or other factors. This vulnerability affects the care the Department must take to avoid being found legally liable for negligence’ (DHS 2000, p.5).

Neither the employee’s view nor the quotations from the documents makes a case for suggesting that ‘care’ and ‘involvement’ are mutually exclusive, but in practice it seems to operate like that. It seems as if some people think it is unreasonable or unnecessary for people with
profound impairments to participate in ordinary living.

It may be difficult for those staff and family members who hold the view that people with profound intellectual disabilities are a ‘special population’ to see that they are able to participate in ways that other disabled people can. As well as struggling to see the relevance of these values and policies that underpin ‘participation’, staff may vary in how central they are to their own belief systems (see Rokeach 1968).

Organisations may espouse their values, but they do not prioritise them. Front-line workers take day-to-day decisions about what is important on any particular shift. Not surprisingly physiological and safety needs are routinely privileged over practices that would encourage participation in ordinary living.

The point is well-made by Felce and Perry (1995) that the claim that people want to take responsibility for the conduct of their own daily lives has to be accepted by the staff working with people with severe and profound intellectual impairments and applied in their everyday practice.

What may be well-articulated in the literature may not have been articulated at all for front-line staff. It seems necessary to spell out the rationale for service goals in minute detail, as Jones et al. (2001) do in their explication of the assumptions underpinning active support that, ‘Active support tends towards the assumption that people would prefer to be occupied than not and to undertake the same range of activities as other people, unless they have given a contrary indication’ (p.356).

Again, front-line staff working with people with profound impairments will have to accept this argument.

Being reminded that these arguments need to be accepted by people is an important point if the ideas are so ingrained that you now barely conscious of the arguments outlined above. If we are confident that there are best, or at least better ways, of delivering services we need to accept that the arguments need to be won time and again and service managers, especially those supervising front-line employees, need to become skilled at putting those arguments across, so that people accept and find ways of incorporating them into their practices.

This means looking at ways of making the Department’s espoused values ‘practical guides for action’ for people supporting residents with profound intellectual disabilities but in some instances it also means critically examining the premises that underpin the espoused values and ask whether they are the ‘right’ values.

Choice

In the our writing about the Making Life Good in the Community project we have made the point that many of the concepts embedded in the Department’s documents are hard to define and apply, which often means that they are poorly understood and implemented by front-line staff. This gap seems to be more apparent when trying to apply these concepts to the lives of people with profound intellectual impairments. This should not be surprising when philosophers have not resolved some key debates (see Reinders 2000 for example), but this does suggest that not enough attention is given to working through the issues in a way that can be understood and applied by front-line staff.

We have suggested that it is therefore important to reflect on the Department’s values and standards in terms of their feasibility and generalisability. It is difficult not to agree with values and standards in principle or conceptually, but putting them into practice requires careful consideration of the context in which people are living their lives, the needs of particular individuals and the skills and knowledge of the people around them. This seems particularly apparent when looking at the notion of ‘choice’. The concept of choice features heavily in disability services’ rhetoric. It appears in one of the State Disability Plan’s four guiding principles. People should pursue a lifestyle of choice, participate in activities of their choice, live independently if they choose to do so, have a choice about support providers, and be able to choose where they live, with whom, and in what type of housing (State Government of Victoria 2002).

My reading of the ‘tone’ of the State Disability Plan is that is assumes that all disabled people have equal ‘capacity’ as human beings, and therefore as a framework it provides a guide for interactions between people who are free and equal. As such it probably reflects the aspirations of a society that wants to take pride in treating all of its citizens as equals and the ambitions of the plan’s authors to give all disabled people the same moral standing as human beings. Clegg (2003) argues that even in the face of evidence to the contrary that intellectual disability culture is dominated by the belief that service-users have apparently limitless potential to develop skills and autonomy if only they are given the right help. Unfortunately the implementation of this conceptualisation of choice faces serious difficulties for all disabled people. The State Disability Plan marginalises the impact of profound intellectual impairment, where there are significant limitations in people’s intellectual functioning and adaptive behaviours (Luckasson et al. 2002). The word ‘profound’
(and severe for that matter) appears once in the State Disability Plan, in a section informing what the Government will do to build more inclusive communities. The Government will, ‘Introduce a companion card scheme to assist people who have a severe or profound disability to access recreation and leisure opportunities’ (State Government of Victoria 2002, p.26).

Profund intellectual impairment affects a person’s capacity for human agency, the power of reason, and free-will, which is why they are sometimes excluded from conceptions of personhood (Reinders 2000).

Although there has been a significant amount of research on choice and people with profound intellectual impairment (Kearney & McKnight 1997; Lancioni, O’Reilly & Emerson 1996) there are doubts as to whether the concept of ‘choice’ has any relevance to people with a profound intellectual impairment who may not be able to intentionally communicate their reactions to an event (Ware 2004). When you actually look at what people ‘do’, their actions have little or no relationship to the rhetoric on choice. The best we may be able to achieve with ‘such people’ is to reliably interpret their reactions to events and name them likes and dislikes. A dominant assumption in the organisational rhetoric, that all disabled people have equal ‘capacity’ as human beings fails to stand up in practice.

The rhetoric of the State Disability Plan sets up expectations about choice without providing any guidance as to how this might be achieved. These expectations are repeated in other documents. The Direct Care Staff Handbook gives this directive about preparing meals to employees:

‘Although residents need support and supervision, they should be involved in planning and preparing their own meals wherever possible. Staff should not impose their own standards, but educate residents so they can exercise choice and responsibility over the food they eat.’

(p.16)

Front-line workers must shoulder the burden and receive easy, but possibly unwarranted criticisms when they fail to deliver.

We may not know whether people with profound intellectual impairments are participating in activities of their choice, let alone pursuing a lifestyle of choice. It may be impossible to get such a person’s ‘view’ of a trip to the supermarket when he or she does not have the cognitive ability to construct an opinion. Smiling whilst being driven around in a car is not a person expressing a view that they want to participate in that activity. We cannot instantly assume that a negative reaction to sitting in a café means that a person does not want to participate in the activity. The desire to attribute choice-making to all people with intellectual disability may stretch the boundaries as to what some people sensibly class as choosing.

Communication at this level requires both guesswork and inference on the part of the observer, where establishing how a person with profound intellectual disabilities and multiple impairments expresses likes and dislikes is an inexact science (Nind 2001). We may come to be able to state that a particular person seems to like shopping at Coles, being in a car, and going to the local café for a drink, but our ability to determine a person’s ‘views’ about where they live, with whom, and in what type of housing will be even less certain. Ware (2004) argues that we need to be realistic about the degree that we can learn about the views of those with profound impairment.

‘With regard to major life decisions, we may do a more adequate job of deciding what an individual with profound and multiple learning disabilities would prefer, by taking into account a range of assessment information than by trying to ascertain their views by methods which involve a high degree of inference.’ (p.178)

This suggests that we must be cautious about how we interpret the behaviours of people with profound intellectual impairments. Interpreting a person’s behaviour as choice may say more about the values and beliefs of the interpreters than the individual’s actual intentions.

Although it may be desirable that the rhetoric should recognise equal moral standing of all disabled people, we need to more clearly recognise the differential treatment and practice in service delivery. As Sinason (1992) wrote, ‘If we cannot bear to see when someone needs different provision verbally and practically we all end up being stupid’ (p.53).

Footnotes

1 Terminology is fraught with problems. I have used the term ‘people with intellectual disabilities’ where I can, because I think it best works against the process of essentialism. The ‘people first’ prefix emphasises both a common humanity and the diversity of humankind. I refer to ‘impairment’ when I am specifically suggesting that having an intellectual impairment can result in personal restrictions. I also use the term ‘disabled people’ which is a pan-impairment term promoted by some factions of the disability movement that has helped to develop the sense of a shared cultural identity between people with different impairments and is intended to signify that social arrangements cause disability.
The belief that organisation’s need to clarify their value system is succinctly captured by this senior executive in Peters and Waterman’s (1982) book In Search of Excellence:

‘I firmly believe that any organization, in order to survive and achieve success, must have a sound set of beliefs on which it premises all its policies and actions. Next I believe that the most important single factor in corporate success is faithful adherence to those beliefs. And, finally, I believe if an organization is to meet the challenge of a changing world, it must be prepared to change everything about itself except those beliefs as it moves through corporate life.’

Getting to grips with the ways in which values influence practice is problematic. Not least because the area is clouded by the lax operationalisation of the values construct (Stackman, Pinder & Connor 2000). In their article Values, attitudes and service ideology Emerson et al. (1994) used values, attitudes and beliefs interchangeably, ‘to refer to a set of beliefs held by an individual concerning the social worth or value of another individual or group of individuals and the meaning or interpretation of their behaviour’ (p.211). It is beyond the scope of this paper to clearly distinguish between terms that are used interchangeably in much of the service literature and everyday speech. Stackman et al. write, ‘Conceived as global beliefs, values are neither attitudes nor behaviours. Instead, they are the building blocks of the behaviour of and the choices made by individuals. Attitudes, on the other hand, are cognitive and affective orientations toward specific objects and situations. Behavior is the manifestation of a person’s fundamental values and corresponding attitudes’ (p.39).

A root word appears as a number of variations. ‘Include’ (5), ‘included’ (4), ‘includes’ (6), ‘including’ (12), and ‘inclusion’ (7) were aggregated with ‘inclusive’ (28), the variant that best describes a value.

The practice of classifying people with intellectual disabilities into the four sub-groups of mild, moderate, severe, and profound on the basis of IQ tests was dropped by the American Association on Mental Retardation (AAMR) in 1992. The aim was to discourage descriptions of needed supports. Luckasson et al. (2002) write that this was the most criticised aspect of the 1992 AAMR revised definition.

Making Life Good in the Community is a 3-year project funded by DHS that is exploring how we support people who used to live at Kew Residential Services to lead good lives in the community.

The social model of disability with its emphasis on confronting oppression, cultural rights, identity politics, political activism, peer-support, peer-advocacy, self-empowerment, disability culture, disability arts, and disability pride (see Barnes, Mercer, & Shakespeare 1999) has been more open to ideas in the general environment and mirrors dominant modes of political expression during the 1980s more closely that intellectual disability ‘ideology’.

Furedi (2004) writes, ‘Social inclusion is one of those fashionable concepts like transparency and accountability, which everyone uses but rarely defines. Virtually every policy claims to be inclusive, and it is rare to hear any figure in authority attack attempts to institutionalize social inclusion. As a result, social inclusion is generally accorded the status of a public virtue. As noted previously, policies of inclusion are underwritten by the political elite’s desire to establish or re-establish a point of contact with an otherwise atomized and disengaged public. There is nothing objectionable or unworthy about this motive. The problem is that this policy rarely directs attention to the fundamental social, economic and cultural causes of people’s estrangement from many of the key institutions of society. Instead, inclusion is represented as a psychological process of validating people in order to make them feel good’ (p.120-121).

This section draws upon Clement, Bigby and Johnson (2006).

Schwartz attributes this understanding of certainty to Ivan Illich.

There are any numbers of reasons why we ascribe people with profound impairment the same moral standing as human beings. Reinders (2000) gives a number of social reasons:

- Including people with profound impairment in our public morality will strengthen respect for its core values.
- Excluding people with profound impairment would undermine the respectability of institutions in the public eye and may have destabilising effects.
- The ‘full’ members of the community will be better off by including people with profound impairment because it will foster general respect for its institutions.

Sinason (1992) argued that we have a cultural inability to confront realities of intellectual impairment. One manifestation of this is the constant revision of terms for intellectual disability. ‘Each worker introducing a new term hopes that the new word brings new hope and a new period of healthy, historical change. Each time the new word is coined, it is coined honourably. It is not deliberately created as a euphemism but because of the painfulness of the subject’ (p.40).
References


**Appendix A**

**Vision**

‘The Victorian Government’s vision for the future is that:

By 2012, Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria’ (State Government of Victoria, 2002, p.5).

**Mission**

‘The Disability Services Division aims to improve the quality of life of Victorians with a disability through services that enhance independence, choice and community inclusion. To achieve this goal, the division plans and funds a range of supports for people in Victoria with intellectual, physical, sensory and dual disabilities, neurological impairments and acquired brain injury’ (DHS, 2005, p.38).

**Core values (in DHS, 2002b)**

<table>
<thead>
<tr>
<th>Core values</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client focus</strong></td>
<td>‘We work towards improving the health and wellbeing of our clients and community’.</td>
</tr>
<tr>
<td><strong>Professional integrity</strong></td>
<td>‘We treat all people with dignity and respect’.</td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td>‘We strive to do our best and improve the things we do’.</td>
</tr>
<tr>
<td><strong>Collaborative relationships</strong></td>
<td>‘We work together to achieve better results’.</td>
</tr>
<tr>
<td><strong>Responsibility</strong></td>
<td>‘We commit to the actions we take to achieve the best possible outcomes for our clients and community’.</td>
</tr>
</tbody>
</table>
**Victorian Standards for Disability Services (listed in DHS, 2002a)**

<table>
<thead>
<tr>
<th>Standard</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standard 1: Service Access</strong></td>
<td>Each client seeking a service has access to a service on the basis of relative need and available resources.</td>
</tr>
<tr>
<td><strong>Standard 2: Individual Needs</strong></td>
<td>Each client receives a service, which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.</td>
</tr>
<tr>
<td><strong>Standard 3: Decision Making and Choice</strong></td>
<td>Each client has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.</td>
</tr>
<tr>
<td><strong>Standard 4: Privacy, Dignity and Confidentiality</strong></td>
<td>Each client’s right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.</td>
</tr>
<tr>
<td><strong>Standard 5: Participation and Integration</strong></td>
<td>Each client is supported and encouraged to participate and be involved in the life of the community.</td>
</tr>
<tr>
<td><strong>Standard 6: Valued Status</strong></td>
<td>Each client has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.</td>
</tr>
<tr>
<td><strong>Standard 7: Complaints and Disputes</strong></td>
<td>Each client is free to raise and have resolved, any complaints or disputes he or she may have regarding the service provider or the service.</td>
</tr>
<tr>
<td><strong>Standard 8: Service Management</strong></td>
<td>Each service provider adopts sound management practices, which maximise outcomes for clients.</td>
</tr>
<tr>
<td><strong>Standard 9: Freedom from Abuse and Neglect</strong></td>
<td>Each client has the right to be free from physical, sexual, verbal and emotional abuse and neglect. Essentially, people with disabilities have the same rights and responsibilities as all members of the community. Assisting people with disabilities exercise their rights is an important part of your job.</td>
</tr>
</tbody>
</table>

**State Disability Plan’s guiding principles, goals, and priority strategies (State Government of Victoria, 2002)**

<table>
<thead>
<tr>
<th>Guiding Principles</th>
<th>Goals</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pursuing Individual Lifestyles</td>
<td>Reorient disability supports</td>
<td>个体化计划和支持</td>
</tr>
<tr>
<td>Building Inclusive Communities</td>
<td>Develop strong foundations for disability supports</td>
<td>发展和保护人的权利</td>
</tr>
<tr>
<td>Leading the Way</td>
<td>Promote local communities</td>
<td>增强地方社区</td>
</tr>
<tr>
<td>Individualised Planning and Support</td>
<td>Strengthening Advocacy</td>
<td>增强倡导</td>
</tr>
<tr>
<td>Having More Choice about Housing</td>
<td>Ensuring Supports</td>
<td>确保支持</td>
</tr>
<tr>
<td>Strengthening Partnerships</td>
<td>More Accountable to People with a Disability</td>
<td>更加可靠的人与残疾人合作</td>
</tr>
<tr>
<td>Targeting Disability Supports</td>
<td>Enhancing Protections and Safeguards</td>
<td>提高保护和保障</td>
</tr>
<tr>
<td>An Industry Plan</td>
<td>Building More Inclusive Communities</td>
<td>行业计划</td>
</tr>
<tr>
<td>Improving Quality</td>
<td>Participating in the Community</td>
<td>建立更多包容性社区</td>
</tr>
<tr>
<td>Strengthening the Workforce</td>
<td>Integrated Planning</td>
<td>参与社区整合规划</td>
</tr>
<tr>
<td>Reviewing Legislation</td>
<td>Promoting Inclusive Education</td>
<td>宣传包容性教育</td>
</tr>
<tr>
<td>Access to Public Transport and Buildings</td>
<td></td>
<td>公共交通和建筑的接入</td>
</tr>
<tr>
<td>Improving Health and Well-being</td>
<td></td>
<td>提高健康和福祉</td>
</tr>
<tr>
<td>Increasing Employment Opportunities</td>
<td></td>
<td>增加就业机会</td>
</tr>
<tr>
<td>Working Together</td>
<td></td>
<td>一起工作</td>
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</tbody>
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Defining And Measuring The Outcomes Of Inclusive Community For People With Disability, Their Families And The Communities With Whom They Engage.

Erin Wilson, Scope

Work Towards Inclusive Communities: A Non Government Organisational context

This paper focuses on the context of a major non government disability service provider. Scope (Vic) is a not-for-profit organisation providing disability services throughout Melbourne and Victoria to more than 4,500 children and adults with physical, intellectual and multiple disabilities. Additionally, Scope works with a range of community agencies to enhance their capacity to offer services and support to people with a disability. Scope (Vic) is one of the largest disability agencies in Victoria, with an annual budget of around $50M, 1300 staff, and over 100 sites around Victoria.

Scope has recently endorsed a new Strategic Plan that articulates a vision and strategic direction around supporting people with disabilities to achieve their potential in welcoming and inclusive communities (Scope, 2005, p. 3). Scope’s strategic plan articulates a broad framing of inclusion that moves beyond an understanding of inclusion as ‘participation’ in a range of community activities and life domains, towards a vision of a reconstituted community that is fundamentally different in the way it understands its membership and the activities, rights and responsibilities of these members. In this way, Scope’s conceptualisation of ‘inclusion’ is consistent with, though moves beyond, the understanding implied in concurrent Victorian State Government policies on disability where ‘access’ and ‘participation’ are synonyms for inclusion.

Given this interest in creating welcoming and inclusive communities, along with people with disability achieving their potential within them, Scope has begun work to develop an outcomes measurement framework to map achievements and change in these arenas. Inevitably, measurement of outcomes is dependent on understandings of inclusion.

In order to appropriately contextualise Scope’s outcomes measurement research, this paper begins with an articulation of the various understandings of inclusion including those emerging within Scope, and those existent in literature and Victorian State Government disability policy.

Broader Definitions of Inclusion

The literature on inclusion is both broad and extensive, and encompasses a number of key framings. ‘Inclusion’ can be understood as a concept in its own right, embracing a range of understandings, or partnered with other concepts, such as ‘social inclusion’ or ‘community inclusion’ to foreground a particular set of concepts and values. Whilst this paper lacks the space to offer a detailed analysis of the literature on inclusion, it is important to summarise the understandings relied upon for this paper. Schleien, Green and Stone (1999) provide a useful distinction of three characteristics of inclusion which provide a fruitful way of distinguishing between definitions in use. They argue that ‘the concept of inclusion may best be viewed as a continuum that includes three levels of acceptance’ (p. 1). They define these levels as: 1) physical integration, being the right to and actuality of physical accessibility; 2) functional inclusion as the ‘ability to function successfully’ in given environments; and 3) social inclusion as social acceptance and participation in ‘positive interactions’ with others (pp.1-2).

Smull and Sanderson (2001) similarly make this distinction for the success of outcomes in person centred approaches. They discuss the continuum of inclusion utilising the notion of an individual ‘being present’ in an event or community, ‘having presence’, and ‘actively participating’ (Smull & Sanderson 2001, p. 139). Such schema draw on and echo critiques of ‘integration’ which contrast physical integration as physical location, or presence, of people with a disability in communities, (particularly via non institutionalised settings), and social integration which involves both the quality of personal relationships as well as ‘sense of’ connectedness to communities of choice (Cummins & Lau 2003). Adding to this schema the literature on person centred approaches within disability services, suggests that, at all times, determining the meanings of any point on such continuums will be highly personalised, contextualised and therefore widely divergent across the disability population.

Whilst the inclusion literature ranges widely beyond these conceptual framings, this set of concepts - that emphasises distinctions between physical presence and a range of social and participative outcomes which are highly individual in nature - provides a useful scaffolding for analysing the definitions underpinning existing policy discourses.

Overview of the Policy Context: How Community Inclusion and Outcomes of This Are Understood.

Policy influences practice in at least two ways: it can determine what service models and
initiatives are funded; and, it provides a standards monitoring and compliance framework to which funded services are accountable. This policy context provides a useful data set to analyse prevalent understandings and priorities around inclusion. It also provides a contrasting context to Scope’s understanding of inclusion, as generated through dialogue with people with disabilities and the communities they engage with.

There are two significant policy domains which influence the work of the disability sector in Victoria and the development of outcome measures in this arena: 1) the Commonwealth policy environment, and 2) the State Government policy environment.

At the Commonwealth level, disability services are currently operating within the third Commonwealth State Disability Agreement (CSTDA). This Agreement specifies five national strategic policy directions along with performance monitoring and reporting requirements. The most recent Audit Report of the Auditor General (Commonwealth of Australia 2005) identifies a significant shortfall in regard to measuring outcomes specified in the CSTDA. In particular, it identifies a core objective of the CSTDA in the following way:

The Commonwealth and States/Territories strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community.

(Commonwealth of Australia 2005, p.11)

The Report identifies that as yet ‘no indicators of the quality of life of people with disabilities, their participation in the community, their value in community, or any related parameters’ are included in the performance framework of the CSTDA (Commonwealth of Australia 2005, p. 16). Development in this area is part of Recommendation 1 of the Report. This echoes concerns raised by the Steering Committee for the Review of Government Service Provision in its 2004 report, which identified that no State/Territory had effective measurement indicators or methods to assess quality of life, wellbeing or social participation of people with disability. This discussion utilises the terminology of participation and social value rather than inclusion, but broadly affirms this arena as a key goal of government funding. Additionally, these findings provide a clear Commonwealth policy directive for immediate work in the area of development of measurement indicators and methods to do with quality of life and social participation for people with a disability. Despite this, it is not clear what role the Commonwealth government might have in addressing this omission.

At the Victorian State Government level, the disability policy discourse proposes a view of community inclusion as largely one in which people with a disability have access to and participate in communities of people without a disability. Whilst the goals of the Victorian State Disability Plan 2002-2012 suggest that people with a disability should ‘have the same opportunities as all other citizens’ across social, economic, cultural, political and spiritual life domains (Department of Human Services (DHS) 2002, p.11), this is quickly reinterpreted somewhat more narrowly as access, participation and decision making control.

The Revision of the Victorian Standards for Disability Services (DHS, 2006a) consistently frames community participation and inclusion as occurring in communities in which people with a disability are largely absent at present. Whilst this addresses social justice and equity goals, it simultaneously negates the value of the multiple communities with which people with a disability currently engage including communities comprised of peers, paid workers, families and others. The revised Standards identify five outcome domains as follows:

1. Individuality... a person having individual characteristics, goals, wants, aspirations and support needs.
2. Capacity... identifying and encouraging a person’s abilities and potential whilst recognising their lifestyle and cultural diversity.
3. Participation... a person’s engagement and involvement in their community.
4. Citizenship... the individual being part of a community where all members have equal rights and responsibilities.
5. Leadership... direction setting and showing the way. This concept applies equally to individuals, support providers, communities and government agencies.

(DHS, 2006a, p.6)

1Interestingly, the area of client decision making control is frequently linked to measures of service responsiveness. In such cases, it is suggested that where services appear responsive to client preferences, this is an indicator or clients having decision making control and choice. Unfortunately the two are not synonymous and such proxy measures that equate client choice with service responsiveness risk emphasising the agency of service provider at the expense of the agency of the person with a disability.
The latest Revised Quality Framework for Disability Services, Draft Evidence Indicators (DHS 2006b) is part of a further development of the Revised Standards and further reduces their parameters. In this subsequent draft Quality Framework (DHS 2006b), the ‘Outcome Principle’ for the above standard of Participation is defined as:

*Each individual is able to access their community.*

(DHS 2006b, p. 1)

Its matching ‘Outcome Standard’ is likewise understood as

*Support providers work with individuals to assist them to actively engage in their community.*

(DHS 2006b, p. 1)

Within this policy definition, participation and engagement are synonymous with access or physical location. Whilst some of the principles and outcomes definitions of other standards (such as for Capacity) remain less rigidly defined, they do not in any way direct attention to an overt and broad understanding of the life domains in which people with disabilities might exercise or increase their capacity or meet their individual needs. Despite this, DHS has significantly expanded their focus from that of previous Standards. Whilst the limitations of these most recent *Revision of the Victorian Standards for Disability Services* may reflect a pragmatic and incremental approach to change management, it paves the way for (but does not yet achieve) a more ambitious framing of outcomes for people with disabilities and the communities with whom they engage.

**Scope’s Emerging Framework of Outcomes**

Against this discourse of community inclusion, Scope commenced work to define and identify methods of measurement for outcomes related to both the building of inclusive community (Scope strategic priority 2) and the outcomes of person centred approaches (Scope strategic priority 1). Whilst these two priorities are interdependent, this discussion will focus only on the definition and measurement of inclusive community.

At the outset of this work it was apparent that: i) the indicators and measurement methods proposed in the *Revision of the Victorian Standards for Disability Services* (DHS, 2006) were insufficient to capture the range of experience and aspirations encountered amongst Scope clients; ii) that these aspirations could be aligned to diverse fields of academic literature (eg. to do with quality of life, wellbeing, citizenship, social capital, community belonging etc.) and iii) that whilst there were efforts to identify and measure the ‘health’ or ‘resilience’ of identified communities (for example, by local governments), there appeared to be no significant work being undertaken to identify the outcomes community members experienced as a result of engaging with and ‘including’ marginalised groups such as people with a disability. Whilst this last is a significant focus of the Scope outcomes measurement research, it will not be further discussed here. This discussion will focus attention on definitions of outcomes for people with a disability.

An early literature review of outcome definitions across a range of fields including that of disability, led Scope researchers to the conclusion that existing tools do not map the breadth of life experience and aspiration of people with a disability. Many tools, necessarily, respond to the context of their creation. This has meant, in some cases, a predominant focus on basic human right issues and outcomes, responding to the lack of privacy, safety and autonomy in, often institutional, settings. While these outcomes foci are critically important, Scope researchers immediately witnessed a disjuncture between them and the broader outcomes being daily reported by clients and staff in Scope. Scope staff and clients were reporting, for example, aspirations and outcomes for people with a disability around sexuality, consumer roles, political influence, influencing community attitudes (often via agency in cultural activities), forging changes in public spaces, among others.

As part of the strategic planning process within Scope, it was also clear that significant changes in the disability sector would be occurring over the next five to ten years (and beyond). The development of an outcomes framework, with fully tested methods and tools, would itself take three to five years. This suggested that any outcomes measurement framework needed to look beyond the immediate activities, priorities and outcomes of the present to forecast the range of these in the future. As a result, the project team decided to adopt a working or emerging model that sought to articulate outcomes across a full range of life domains: personal wellbeing and civil citizenship; social citizenship; economic citizenship; political citizenship; cultural citizenship; and environmental citizenship. These domains seek to frame the major areas in which each target group (i.e. people with a disability, families and support circles, and communities) aspire to and experience outcomes. The domains are analytical and conceptual device to assist in articulating and affirming the range of these aspirations and experiences. They are, of course, interconnected and overlapping in many ways.

As part of this working model, the project team has taken the notion of citizenship, with its long history of definition stemming from Marshall (1950), and adapted it somewhat to suit our purposes. The notion of citizenship used here, builds on historical views of citizenship formed...
Overview of outcomes measurement literature relevant to disability

During 2005 Scope undertook a broad scale literature review. Given the scale of literature dealing with outcomes definition and measurement, the review focused on literature explicitly identifying outcomes for people with a disability, along with recent literature in person centred approaches to practice within disability (given the prevalence of this practice model in the field). It also drew on literature in the field of Early Childhood Intervention, again given the significant focus this area of practice receives in the disability field. Finally, the review encompassed a spattering of key literature in the broader fields of social capital, social network, citizenship and quality of life.

The intention of the review was to: i) identify definitions of outcomes and their sub domains; and ii) identify methods of measurement in use. Additionally, researchers divided outcomes according to outcomes focusing on individuals, outcomes focusing on small but specific cohorts (eg particular service users), and outcomes related to a large population set (eg local government area). Following this broader review, an analysis of outcome definitions was undertaken using the Scope emerging outcome framework as an organising tool. It is this analysis that is summarised here, rather than a critique of the literature it documents. The analysis is illustrative in evidencing the kinds of outcomes focused on in the literature to date. Whilst this focus relates to contextual and historical factors, unfortunately it also continues to unwittingly limit and confine the way outcomes are understood for people with a disability.

The analysis evidences that outcome definition and measurement data is dominant in the domain of Personal Wellbeing. Far less attention appears to have been paid to the areas of Economic, Political, Cultural and Environmental citizenship, and where it has, outcome definitions remain limited. For example, in the economic domain, activity has focused on the areas of employment, poverty, and education/training, largely ignoring the range of economic roles available including industrial relations, consumer, property owner, etc. Some of this imbalance or neglect could be attributed to the choice of literature surveyed. However, it is the author’s contention that a larger scale review would reveal similar conclusions which largely reflect, as well as contribute to, the ongoing preoccupation of service providers, funders and policy makers with limited understandings of inclusion and life potential for people with a disability.

This paper will present the analysis of two of the dominant outcomes measurement frameworks in use within disabilities to evidence the above proposition. The Personal Outcome Measures framework (Accreditation Ontario 2000) identifies eleven (11) of its twenty five measures in the domain of Personal Wellbeing. Allowing for some overlap, a further eight (8) relate to Social Citizenship, one (1) to Economic Citizenship, two (2) to Political Citizenship, one (1) to Environmental Citizenship, and none (0) to Cultural Citizenship. Likewise, the National Core Indicators project in the USA reports a similarly constrained spread of what they term ‘consumer’ and ‘health, welfare and rights’ outcomes (Human Services Research Institute 2003, pp. 1 & 8). Unlike the Personal Outcome Measures framework, the National Core Indicators framework provides indicators relevant to individuals, specific cohorts and larger populations (note that only those listed for individuals are recorded in Appendix 1 attached). Outcomes can be categorised across the Scope domains as follows: fifteen (15) in the domain of Personal Wellbeing; ten (10) in
<table>
<thead>
<tr>
<th>Outcome Domain</th>
<th>Definition</th>
<th>Key ideas/sub domains</th>
</tr>
</thead>
</table>
| **Personal wellbeing and civil citizenship** | The quality of personal life including health, wellbeing, happiness, autonomy, control and choice over identity, future, beliefs, values, thought, expression and spirituality. | Quality of life  
Personhood, identity construction – sense of self  
Happiness  
Self esteem  
Wellbeing  
Health and safety  
Freedom of thought, expression, speech  
Individuality  
Autonomy  
Choice  
Self determination  
Individual freedoms: Liberty, Speech, Thoughts and Faith, Conclude valid contracts, Justice, Values, Beliefs |
| **Social Citizenship**               | The quality of life in the social domain including a person’s agency (to make meaning, act, influence and contribute) in the areas of relationship, community connectedness and belonging. | Networks:  
• bonding (horizontal / closed)  
• bridging (between groups)  
• linking (to authority)  
Relationships  
Friendships (intimate -> acquaintances)  
Community connectedness/ belonging  
Community inclusion  
Loneliness, isolation |
| **Political Citizenship**            | The quality of life in the political domain including a person’s agency (to make meaning, act, influence and contribute) in the areas of public decision making, civic activity, consultation, advocacy and lobbying. | Civic activity  
Civic duties: rights and responsibilities  
Advocacy, Lobbying  
Democracy  
Choice  
Leadership  
Political participation |
| **Cultural citizenship**             | The quality of life in the cultural domain including a person’s agency (to make meaning, act, influence and contribute) in the areas of cultural production and participation, broader attitude change and development, and recreational activities. | Participation in cultural or recreational events and activities.  
Influencing attitude / behaviour change  
Cultural production:  
• Performance  
• Art  
• Writing / authorship |
| **Economic citizenship**             | The quality of life in the economic domain including a person’s agency (to make meaning, act, influence and contribute) in the areas of employment, education / training, a range of economic roles (e.g. as consumers and income generators). | Access to economic domain  
Employment  
Education and training  
Consumer roles  
Home/ property ownership  
Income level and source  
Direct payments  
Retirement  
Industrial relations agency |
| **Environmental citizenship**        | The quality of life in the environmental domain including a person’s agency (to make meaning, act, influence and contribute) in relation to their environment including constructed environments, public and private space. | Access to physical environment  
Shaping of/ access to public space  
Shaping of/ access to private space (housing etc)  
Shaping of/ access to public transport  
Built environment / constructed space  
Universal design |
the domain of Economic Citizenship; six (6) in the domain of Social Citizenship; six (6) in Political Citizenship; one (1) in Environmental Citizenship; and none (0) in Cultural Citizenship. Reviewing the pool of outcome indicators from the breadth of literature reviewed, it is evident that most work has concentrated on the area of personal wellbeing and autonomy, followed by some interest in social, political and sometimes economic outcomes. Almost no attention, in the field of outcomes definition, has been paid to the areas of environmental or cultural agency. These results are summarised in Appendix 1 that provides a snapshot of outcome indicators for individuals (excluding those related to cohorts or larger populations).

The Lived Experience – Aspirations and Outcomes for People With Intellectual Disability in Scope

Throughout the development of the Scope framework to date, researchers have engaged with the stories of staff, clients and families about the aspirations people with a disability hold and the outcomes they achieve. In particular, the process of implementing both Person Centred Planning and Individualised packages within the organisation has provided a range of case studies to analyse, prior to a more rigorous data collection and analysis process focusing on a wider range of Scope clients, family and community members.

This section aims to offer a short selection of case studies to evidence the diversity of outcomes currently experienced by Scope clients with intellectual, multiple and complex disabilities, as well as some of the associated issues of practice and policy related to them.

Tom

Tom is a young man in his twenties with a lively sense of humour and keen interest in an active social life. He lives with his mum, has previously battled with the system, and suffered bouts of depression and severe pain. He utilises an electronic aid to communicate, and uses a wheelchair for mobility. Over the past two years, Tom has radically changed his life with the support of a person centred planning process, among other things. He has aspired to be employed, be recognised as an independent person and have opportunities to interact with people his own age. He now works one day per week in a bank as a mail clerk, has commenced painting and is now making a modest income from selling his art. He undertakes volunteering at a local library (having overcome policies around police checks and a requirement to physically sign his name which he is unable to do), and has a key to his own car (driven by his driver). He is a member of the local bowling club and enjoys a wide range of relationships with people in each of the areas in which he participates. He sees himself as a changed man, his pain is lessened and his outlook positive. His relationship with his mother has also changed as both have been able to move on with more independent lives.

Using the Scope emerging framework, it would appear that Tom has experienced outcomes in a range of domains. He has significant economic outcomes, gaining employment, participating in art training, and earning an income from self employment as an artist. In the civic domain, he is exercising his rights and responsibilities as a citizen and contributes to community services via his volunteering role. His achievements have led to outcomes in the personal wellbeing domain (i.e. lessened pain, and increased autonomy), and in the social domain through positively changed relationship with his mother and increased relationships with others. He enjoys cultural and recreational outcomes from his bowling and artistic activities.

Lennette

Lennette is an older woman who is keenly interested in people and travel. Her aspiration has been to travel on the Very Fast Train. She has intellectual and physical disabilities and uses a wheelchair for mobility. Her communication style includes some verbal articulation and gestures. For many years she has attended a day centre program from which she seeks a change. Using a flexible options approach, her day service funds have been somewhat reallocated to assist Lennette achieve the outcomes she aspires to. She now uses the train (not the Very Fast Train) to travel to regional Victoria on a weekly basis. She does this independently and has developed a network of acquaintances whom she visits and interacts with. She gets much enjoyment from seeing the sights and moving around the train stations and community.

Using the Scope framework, Lennette has achieved outcomes in the social, personal and cultural/recreational domains. Additionally, she has also achieved outcomes in the economic domain, enacting a desired role as a consumer, tourist and traveller.

These experiences are not well captured by the Personal Outcome Measures framework (Accreditation Ontario, 2000). Whereas this framework would enable Tom and Lennette to report outcomes generally in terms of choosing and realising personal goals, and satisfaction with
personal life situations, it does little to adequately document and map the kinds of domains Tom and Lenette engage with or the nature of their contribution. A similar analysis could be made using the Revision of the Victorian Standards for Disability Services (DHS 2006a) or draft Revised Quality Framework (DHS 2006b). This kind of reduction undermines efforts to both affirm and document the lives and aspirations of people with a disability as an active and diverse citizenry.

Other case studies within Scope evidence a wide range of outcomes and achievements of varying levels of satisfaction to the individuals involved. Most, even those with a very low level of achievement against goals, appear to demonstrate outcomes in multiple domains (particularly including that of personal wellbeing, given that the opportunity to make autonomous decisions is a necessary precondition of person centred outcomes). However, practitioners and clients report a similar range of issues and concerns. It remains the case that in many instances clients lack the most basic of influence over the things that matter to them in their life (even choice of soap). Such a history of thwarted autonomy and individuality has resulted in a preparedness to accept the ‘ordinary’, a lack of trust in change and the staff that are required to support it, and an unwillingness to risk again a dream that has previously been repeatedly shattered. To address this, staff report a need for: strongly contextualised and inter-subjective practice; management and policies that actively support such practice (and its risks); staff whose role it is to both build the capacity of others (inside and outside the organisation) and tackle structural barriers; a clear staff role to actively support the plans and aspirations of clients (i.e. ‘keep the plan alive’) despite the barriers; and a sensitivity to the complex and fragile nature of any work that involves entering into relationships between people. Additionally, families, clients and staff report problems in accessing financial resources to support the diverse aspirations of people with a disability, including resources such as appropriate and adequately maintained equipment and aids suitable to aspirations. Additionally, the prevailing discourse of risk management is seen as a significant barrier to the actualisation of the aspirations of people with a disability.

Conclusion
This paper explores an understanding of ‘inclusion’ that emphasises personal agency in a range of life domains. It evidences a lack of policy and outcomes measurement attention in this area. At present, both continue to constrain the way the aspirations and outcomes of people with a disability are supported and documented. In order to progress (and operationalise) this wider understanding of inclusion and the outcomes related to it there is substantial work to be undertaken. There appears to be sufficient evidence to affirm the further development of an outcomes framework utilising a wider range of domains as proposed here. This development work would include both the scoping of the range of outcomes as identified by a wide cross section of people with a disability, families and communities, and the development of appropriate tools to document and ‘measure’ the nature, quality and extent of these. It is hoped that such work will continue to be a catalyst for dialogue among all groups as to how a ‘good life’ for people with disabilities can be understood and achieved.

References


### Appendix One:
Comparison of Outcome Definitions From Literature Review Across Scope Outcome Domains:
Focus on Outcomes for Individuals

<table>
<thead>
<tr>
<th>Personal wellbeing and civil citizenship</th>
<th>Social citizenship</th>
<th>Economic citizenship</th>
<th>Political citizenship</th>
<th>Cultural citizenship</th>
<th>Environmental citizenship</th>
</tr>
</thead>
<tbody>
<tr>
<td>• People choose personal goals&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People have intimate relationships&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People choose where they work&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Cultural belonging&lt;sup&gt;21&lt;/sup&gt;</td>
<td>• People use their environments&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>• People choose where and with whom they live&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People live in integrated environments&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are treated fairly&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Cultural needs of the individual addressed&lt;sup&gt;21&lt;/sup&gt;</td>
<td>• People have got their own house and the support that they want&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>• People are satisfied with their personal life situations&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People participate in the life of the community&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are in paid work or in courses they have chosen&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Cultural rights&lt;sup&gt;21&lt;/sup&gt;</td>
<td>• The power to name, create meaning, construct personal biographies and narratives by gaining control over the flow of information, goods and cultural processes&lt;sup&gt;21&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>• People choose their daily routine&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People interact with other members of the community&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Job satisfaction and pride&lt;sup&gt;15&lt;/sup&gt;</td>
<td>• Community activism including volunteerism&lt;sup&gt;15&lt;/sup&gt;</td>
<td>• connecting individual life stories with wider cultural discourses&lt;sup&gt;21&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>• People have time, space and opportunity for privacy&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People perform different social roles&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People exercise rights&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Political involvement&lt;sup&gt;15&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People decide when to share their personal information&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People have friends&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are treated fairly&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Citizen power&lt;sup&gt;16&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People realise personal goals&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are respected&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Participation in local organisations and solution of local problems&lt;sup&gt;15&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People have the best possible health&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are connected to natural support networks&lt;sup&gt;3&lt;/sup&gt;</td>
<td>• Level of support networks and helping others (numbers, frequency, closeness)&lt;sup&gt;9&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People are safe&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People in people’s lives understand them better and communicate with them better&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Perceived social support&lt;sup&gt;9&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People have the best possible health&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People are more involved in their local community&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Friendships&lt;sup&gt;13&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People are free from abuse and neglect&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• People have richer networks of friends and relationships&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Degree of acceptance (physical integration, functional inclusion, social inclusion)&lt;sup&gt;14&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People experience continuity and security&lt;sup&gt;1&lt;/sup&gt;</td>
<td>• Level of support networks and helping others (numbers, frequency, closeness)&lt;sup&gt;9&lt;/sup&gt;</td>
<td>• Structure and quality of social relations (formality, size, structure, reciprocity)&lt;sup&gt;16&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People say they are happier in their new life&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Perceived social support&lt;sup&gt;9&lt;/sup&gt;</td>
<td>• Frequency of interactions with friends and families&lt;sup&gt;15&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People have more control over their lives&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Friendships&lt;sup&gt;13&lt;/sup&gt;</td>
<td>• Everyday social interactions&lt;sup&gt;15&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• People have done something unexpected not simply followed the path that services laid out for them&lt;sup&gt;7&lt;/sup&gt;</td>
<td>• Degree of acceptance (physical integration, functional inclusion, social inclusion)&lt;sup&gt;14&lt;/sup&gt;</td>
<td>• the number and type of groups and networks of which individuals are members&lt;sup&gt;15&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• levels of participation, reciprocity, feelings of trust and safety; social connections&lt;sup&gt;16&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• ‘Sense of community’ ie. extent to which part of a readily available and supportive social structure&lt;sup&gt;18&lt;/sup&gt;</td>
<td>•</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social capital: participation local community; proactivity; trust/safety; neighbourhood connections; family/friends connections; work connections&lt;sup&gt;19&lt;/sup&gt;</td>
<td>•</td>
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</table>
References for Appendix


Ageing With An Intellectual Disability: Australian Population Patterns

Xingyan Wen
Australian Institute of Health and Welfare

Outline

- Population estimates of intellectual disability
- Ageing trends of people with an intellectual disability and disability service users with an intellectual disability
- Associated health conditions for people ageing with an intellectual disability
- Needs for assistance for people ageing with an intellectual disability
- The experience of people ageing with an intellectual disability in education, employment, housing and community participation.

Table 1. Comparison of population age structures, Australia, 1981 and 2003

<table>
<thead>
<tr>
<th>Age Group</th>
<th>1981</th>
<th>2003</th>
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<td>5-9</td>
<td>8</td>
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<td>6</td>
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<tr>
<td>15-19</td>
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<td>3</td>
</tr>
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<td>25-29</td>
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<tr>
<td>50-54</td>
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<td>60-64</td>
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<td>75-79</td>
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<td>80+</td>
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Table 2. 1981-1993 Age distribution of population estimates of intellectual disability

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<th>Age Group</th>
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<td>30</td>
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<tr>
<td>5-14</td>
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<td>25</td>
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<td>15-24</td>
<td>25</td>
<td>20</td>
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<td>55-64</td>
<td>5</td>
<td>1</td>
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<tr>
<td>65-74</td>
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<tr>
<td>75+</td>
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Population estimates of intellectual disability, 2003

Based on all reported disabling conditions:

- All ages: 588,700 people, or 3.0% of Australians
- Aged under 65: 436,200 people, or 2.5% of Australians of that age
- Aged 65+: 152,500 people, or 6.1% of Australians of that age
- Aged 45-64: 84,400 people, or 1.8% of Australians of that age

Based on all reported disabling conditions plus a severe or profound core activity limitation:

- All ages: 351,000 people, or 1.8% of Australians
- Aged under 65: 215,100 people, or 1.2% of Australians of that age
- Aged 65+: 135,900 people, or 5.4% of Australians of that age
- Aged 45-64: 35,900 people, or 0.8% of Australians of that age
Table 3. Age distribution of population estimates of intellectual disability: 1998 and 2003

Table 4. Age distribution of disability service recipients with an intellectual disability

Table 5. Age distribution in institutional accommodation, 1998 and 2002
Table 6. Age distribution in institutional accommodation, 1999 and 2004

Table 7. Population aged 45 to 64: associated health conditions (1), 1998

Table 8. Population aged 45 to 64: associated health conditions (2), 1998

Table 9. People aged 45 to 64 with a disability: severity of core activity restriction, 1998
Table 10. People aged 45 to 64 with a disability: number of core activities in which help was needed, 1998

Table 11. People aged 45 to 64 with a disability: frequency of need for personal assistance with core activities, 1998

Table 12. People aged 45 to 64 with a disability: need for help with non-core activities (1), 1998

Table 13. People aged 45 to 64 with a disability: need for help with non-core activities (2), 1998
Table 14. Population aged 45 to 64: Year 12 completed, 1998

<table>
<thead>
<tr>
<th>Year completed</th>
<th>Intellectual disability</th>
<th>Total disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>39</td>
<td>39</td>
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</tbody>
</table>

Table 15. Population aged 45 to 64: labour force status, 1998

<table>
<thead>
<tr>
<th>Labour force status</th>
<th>Intellectual disability</th>
<th>Total disability</th>
<th>All persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cared accommodation</td>
<td>12</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Employed</td>
<td>22</td>
<td>39</td>
<td>63</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Not in the labour force</td>
<td>63</td>
<td>56</td>
<td>33</td>
</tr>
</tbody>
</table>

Employment restrictions and their severity, 1998

- Profound – permanently unable to work and no provision could be made to enable work
- Severe – Needed/would need ongoing assistance or supervision at work
- Moderate – Restricted in type of work could do; often needed time off work; restricted in number of hours worked; and difficulty in changing jobs/getting better job
- Mild – Did not need assistance or have difficulties, but needed employer to provide training/retraining, special equipment, modified buildings/fittings, special/free transport or parking.

Table 16. People aged 45 to 64 with a disability: severity of employment restriction, 1998

<table>
<thead>
<tr>
<th>Employment restriction</th>
<th>Intellectual disability</th>
<th>Total disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cared accommodation</td>
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<td>1</td>
</tr>
<tr>
<td>Profound</td>
<td>60</td>
<td>36</td>
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<tr>
<td>Severe</td>
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<td>4</td>
</tr>
<tr>
<td>Moderate</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>Mild or no restriction</td>
<td>5</td>
<td>28</td>
</tr>
</tbody>
</table>
Table 17. Population aged 45 to 64: principal source of cash income, 1998

Table 18. Population aged 45 to 64: housing tenure type, 1998

Table 19. Population aged 45 to 64: marital status, 1998
Unmet need for CSTDA services 2001

Conservative estimates:
- 12,500 people needing accommodation and respite services
- 8,200 places needed for community access
- 5,400 people needing employment support ‘Triangulation’
- 6–24 times more people seeking services than removed from registration/waiting lists

Conclusion
- People with an intellectual disability are ageing.
- The disability experience of people ageing with an intellectual disability is complex and multi-dimensional.
- These factors are creating challenges for the disability, aged care and other human service systems.

Notes

Method of estimation
- A person is included in the estimates of intellectual disability if:
  - A positive response was made by or for them to the screening question about having ‘difficulty learning or understanding things’; and/or
  - A positive response was made by or for them to one of the 17 screening questions and one or more intellectual impairments or disabling conditions was reported.

Disabling conditions: 2003 SDAC data categories
- Intellectual and developmental disorders nfd
- Mental retardation/intellectual disability
- Autism and related disorders
- Developmental learning disorders
- Other developmental disorders
- ADD/hyperactivity
- Down syndrome
- AIHW ...
Implementing State Disability Policy For People With Intellectual Disability

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School of Social Work and Social Policy, LaTrobe University

A comparison of parliamentary second reading speeches that introduce State and Federal Disability legislation over the past 20 years suggests that the broad vision of achieving equal rights for people with intellectual disabilities has been a consistent theme of Australian social policy during this time. Caroline Hogg introducing the 1986 Intellectually Disabled Persons’ Services Act said:

The emphasis in the Bill is on the rights of the intellectually disabled… a primary objective under the Act is to advance the dignity, worth, human rights and full potential of intellectually disabled people

(In Victorian Parliament1986, p. 316)

In the second readings speech of the Commonwealth Disability Discrimination Act, Brian Howe said:

Our vision is a fairer Australia, where people with disabilities are regarded as equals, with the same rights as all other citizens, with recourse to systems that redress any infringement of their rights; where people with disabilities can participate in the life of the community in which they live..... where difference is accepted, and where public instrumentalities, communities and individual act to ensure society accommodates such difference....


In the second reading speech of the Victorian Disability Bill in March 2006 Cheryl Garbut said:

The State Disability Plan outlines our vision for the future, a future in which Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where people with a disability have the same opportunities to participate in the life of the community and the same responsibilities towards society as all other citizens of Victoria….we recognise that services for people with a disability extend across all aspects of living, including housing, transport, education, employment , income support and recreation

(Victorian Parliament 2006, p. 405)

Policy goals have broadened over this time to include a greater focus on community inclusion and participation, more protection from infringements of liberty and abuse, and more explicit recognition that responsibility for successful implementation lies with parts of government and society beyond the realm of community services. During this time too State legislation has adopted the more generic focus on all people with disabilities of the Federal legislation, rather than separate legislation for people with intellectual disability. Debate around legislation suggests while there is some dissent about broad policy goals, it is generally about the means rather than ends (Bigby 2004a). This suggests that the overarching challenge lies in refining and implementing policy rather than designing its broad direction. Despite 20 years of visionary policy, a brief glimpse of key social indicators suggests the enormity of the task that still lies ahead.

For example:

Employment and Income

- 11% of people with intellectual disability, have wages or salary as their principal source of income compared to 47% of all persons (AIHW 2006).
- ‘Fewer people with disabilities participate in the workforce than those without disabilities. More people with disabilities are unemployed than those without disabilities. In 2003, 53.2 % of people with disabilities participated in the labour force as compared to 80.6 % of those without a disability. Since 1993, the labour force participation rate of people with disabilities has fallen, while the rate for people without disabilities has risen’ (Human Rights and Equal Opportunity Commission 2005, p. 2).

- ‘The median income of households with a disabled adult is over 23% below that of a household with no disability and the gap for household with disabled children is even larger, at 36%.... Having a household member with a disability is associated with a substantial increase in the incidence of financial hardship, a higher probability of experiencing severe financial stress.. [and] also leads to less social participation. (Saunders 2005, pp. 6 & 9).

Unmet Service Need

- In Victoria 2559 people with disabilities are on the service needs register for a place in shared supported accommodation, of whom 1051 are classed as being in urgent need. 494 people on the register to access day programs and 1290 people to access in home support (DHS, 2005).

- ‘The number of people waiting for accommodation services, the majority of whom have an intellectual disability, and who are classified by the Department as having urgent or high priority needs, is currently equivalent to approximately 19% of those receiving services’. (Auditor General, 2000, p. 3.)
• Across all States and Territories, evidence suggests that most new services are provided to people with very urgent needs, and between 6-24 times more people are seeking services in 2000/01 than were removed from waiting lists. (AIHW 2002).

Social Inclusion

• Five of the 27 residents relocated to the community had no contact with a family member over a period of 12 months; five of 27 residents had regular contact with a friend or advocate who was neither a family member or a person with intellectual disability (Bigby, Frederico, Cooper 2004).

Disability policy is characterised by major gaps between policy and practice (Bigby & Ozanne 2001; Hardy, Wistow & Rhodes 1990, Lakin 1998; Gates 2001). Reflecting on the first 3 years of the UK policy for people with intellectual disabilities, Valuing People, McNally writes, ‘the gap between policy and its underlying ideology and practice in services remains substantial’ suggesting the policy is ‘rich in ideology and presentation but comparatively poor in implementation’ (2004, p. 327). Acknowledgement by government of this gap however, may be very important to continuing support for visionary policy. To do otherwise, by claiming more than small steps towards a goal, may lead to goals being questioned rather than the speed of progress towards them, as has occurred in debates about cluster housing (Bigby 2004). Somewhat naively in 2001 I wrote, ‘the policy implementation gap in disability is accounted for by either inadequate resourcing or inadequate policy implementation technology and strategies’ (Bigby & Ozanne p 179). The policy implementation literature offers a potentially more finely grained approach to understanding the tasks at hand in policy implementation, the obstacles, tensions and conflicts. It also offers two useful points to bear in mind, firstly that the implementation gap is not unique to disability policy and it is not because ‘the men who run it, either as elected officials, presidential appointees, or high ranking civil servants, are lazy, incompetent or deceitful....they too are puzzled and disillusioned when things go wrong’ (deLeon, & deLeon 2002, p. 6).

This paper uses the Victorian Disability State Plan (Department of Human Services (DHS) 2002) as an exemplar to analyse some of the challenges in disability policy implementation to complement existing thinking about why it is so difficult and how these difficulties might be overcome. It is important to note that this paper is not an analysis of the success or otherwise of the implementation of the State Plan but rather it sets out issues to be considered in the continued planning for its implementation.

The third generation of implementation research and theory has sought to synthesise ‘top down’ and ‘bottom up’ approaches into theoretical frameworks that could capture the complexity of the implementation task and key variables that impact on it (Kaplan & Corbett 2003). For example, Winter (1990) suggests four main socio-political processes determine implementation outcome: character of the policy formation; organisational and inter-organisational implementation behaviour; street-level bureaucrat behaviour and the response by target groups and other changes in society.

This generation of implementation work reconsidered the separateness of policy formation from implementation. For example, it points to the significance that a particular policy and the processes of its formulation has on the implementation process (Winter 1990). It also suggests that implementation shapes, refines and further explicates policy as it involves continuous problem solving and testing of hypothesis (Palumbo & Calista 1990; Winter 1990). deLeon and deLeon (2002) point to an approach based on contingency theory that recognises issues related to implementation vary, by time, type of policy, and units of government i.e. that different policies or socio-economic conditions require different implementation strategies. This indicates the importance of understanding the nature of the policy being implemented, the contextual factors and particular contingencies that surround it and how these might be taken into account during and should inform the processes of implementation.

This paper considers some of key factors about the nature of disability policy, its socio-economic context, and the organisational and inter organisational relations required for its implementations, all of which pose challenges and which may need to be considered as part of implementation.

The Nature of Disability Policy

The nature of the policy gives a sense of its inherent tensions, the conflicts that are likely to emerge as a result of its coherence or dissonance with other policies, and the types of strategies best suited to implementation. A starting point however is the influence of the breadth, complexity and clarity of policy objectives on the implementation process.
Evolutionary Nature of Policy

A top down approach to policy implementation such as the work of Sabatier and Mazanian (1979) conceives policy as having fully articulated goals and stresses the importance of goal clarity to ensure there is no ambiguity about outcomes that are sought. The State Plan clearly is not of this genre, it has extremely broad goals that are full of ambiguity and ill defined concepts such as ‘community’, ‘rights’ ‘inclusion’, and participation. However, a different perspective (Majone & Wildavsky 1979; Bridgman & Davis 2000) conceives policy as evolutionary and places far less emphasis on its initial clarity. This perspective proposes that the policy is a hypothesis, the goals of which need to be tested, refined and adjusted over time. This means policy implementation is a process of adaptation and exploration, learning from experience. From this perspective the broad visionary but essentially fuzzy nature of the goals contained in the State Plan are not problematic, as refining the goals and bringing greater clarity is an essential part of the implementation process as more is understood about the goals and learned about strategies to achieve them.

This approach suggests however that implementation of visionary policy should be regarded as a long term endeavour, that becomes more effective over time as goals or strategies are evaluated and perhaps those seen to be unworkable are adjusted. Such an approach has similarity with the innovation literature that suggests the diffusion of innovation is a long term proposition as knowledge is developed and further refines the original ideas. This understanding has implications in relation to disability policy. If the evolutionary iterative nature of disability policy is accepted then the conditions must be created for learning and feed back to occur. It suggests significant drawbacks in adopting the position that what is essentially policy refinements and adjustment is new policy, fundamentally different from what has gone before. Such a position denies the common links and in so doing breaks the learning cycle by suggesting little can be learned from the past that will inform the implementation of new policy. As the quotes at the beginning of this paper suggest and more thorough analysis of these policies indicate there are strong common threads in intellectual disability over the past 20 years, yet a position appears to have been adopted by government that heralds each iteration as significantly different from what has gone before. For example, notions of individualised planning, have underpinned policies about delivery of services in Australian, UK and US for the past two decades, although terminology and technology has evolved as learning and refinement has occurred (Mansell & Beadle- Brown 2004; Shaddock 2002). If tools such as person centred planning are regarded as embodying essentially new and different policy goals, this potentially cuts off learning and understanding why previous iterations such as general service plans and individual program plans, failed in respect of coverage, implementation and usage, which could be essential in understanding how avoid this occurrence with new tools.

Other examples are found in relation to day support or residential services where new brokerage or supported living models are heralded as offering choice and being individualised, with the implication that such outcomes were not aims or within the capacity of the more traditional day centres or community residential units. A good illustration is found in the State Plan where the New Approach is sharply contrasted with the old rather than being regarded as part of an evolutionary continuum (DHS 2002, p 12). Clearly, however the perspective of evolutionary policy cuts across political imperatives of creating new policies, distinctive from those of predecessors.

If the proposition is accepted that policy and its implementation is an evolutionary process it may also be important to provide space for independent fearless reflection and critique that can be shared by all interested parties. This suggests that evaluation and review be cast more as public research rather than privatised judgements about individual, departmental or organisational performance. In this vein, rather than one of a self interested academic, Parmenter (1999) draws attention to the heavy reliance on contract research and consultancy companies in disability rather than academic/university based research, which can be subjected to peer review, is less likely to be censored and where the intellectual property would be collectively rather than privately owned. Other models here are the UK social services inspectorate that publishes meta findings from service inspections, or the New Zealand Standards and Monitoring Service both of which enable collective as well as individual learning from review and evaluation.

Whilst an evolutionary approach suggests the broad visionary framing of the State Plan may not be inherently problematic it suggests an incremental approach to implementation, which requires the development of greater clarity through articulation of sub-goals, targets and priorities. Theorists such as Lipsky (1980) suggest too the importance of including organisations and street level bureaucrats, (such as first line supervisors, and front line staff), responsible for
on the ground implementation in this process. In this way a link is forged between specific tasks and subcomponents of the policy and the overall vision. It is important for example that staff on the ground are able to see how their work fits into broader visions. In relation to the State Plan this suggests that a part of the implementation processes should be to operationalise and bring greater clarity to the very broad concepts embedded in it. It is perhaps unrealistic to expect street level bureaucrats to resort unaided to first principles to inform their work. Staff need clarity as to the connection to broad visions to understand the significant difference between, for example, community presence and community participation, or between supporting a resident in a group home to prepare a meal and doing it for them whilst they observe. Translation of goals into the conduct of specific tasks or behaviours at street level may also help ensure that particular sub groups of the population are not excluded from the vision. It can be argued that such exclusion is occurring in the current Federal policies of economic participation for people with disabilities that nevertheless excuse unproductive or more severely impaired people with disabilities. This also occurs at a State level, where for example, few exemplars of choice or inclusion are available for people with severe and profound intellectual impairments about whom comments such as ‘that’s alright for x but not - my son – our residents, who are too impaired, whose behaviour is too challenging, who would be too much at risk’ are common.

Broad policy such as that found in the State Plan articulates a vision that requires much more detailed articulation before it becomes a plan of action. This means that implementation must involve the development of more specific policy and implementation strategies around particular issues, groups, life stages. For example, around issues of aging, it will only be by the development of goals, such as ‘residents in group home have the right to age in place’ and testing different strategies that the feasibility of this position will be clarified and the strategies required understood. If further refinement of sub goals of visionary policy does not occur there are always likely to be conflicting interpretations of first principles, as is very evident in aging field at present, where aging in place is understood variously to mean staying at home, or moving within the disability sector, or until it is no longer ‘appropriate’ a term which is not defined at all. (Here I am not referring to detailed ‘policy’ instructions about staff behaviour rather the operationalisation of key values)

Inherent Tensions due to Policy Breadth

The breadth of the State Plan is phenomenal, it seeks to effect change at multiple societal levels - the individual in terms of support to pursue lifestyle of choice, the organisations that deliver support in terms of the choice, quality and individualised nature of that support; the community in terms of acceptance of diversity and relationships among people with and without disabilities, government and non government organisations in terms of policies and structures that support inclusion of people with disabilities. The breadth of the State Plan reinforces the points made in the previous section about the importance of articulating waypoints in terms of sub goals and priorities. It also raises the need to consider whether some goals will be conflicting and whether pursuit of one may potentially undermine another. Perhaps a useful illustration here are the tensions between goals that seek to improve access for people with disabilities to facilities and services available to the whole community and those that seek to maximise lifestyle choices for people with a disability. Lack of experience and opportunities, past discriminatory experiences for example, mean people will chose to attend segregated/special programs as they are within their experience and they feel safer in such programs, yet on the other hand establishment of such groups can be seen contrary to the goal that seeks to change structures and attitudes so people with disabilities do not require ‘special or separate organisations’. Another example is the potential conflict between long and short term goals, illustrated by access to quality medical services. A long term strategy such as training new General Practitioners at undergraduate level to ensure part of their skill set is work with people with disabilities will take many years before it has a major impact on the system. This means that in the shorter term strategies are required to deal with the low level of doctors’ skills and ensure people get high quality care. These may include the establishment of specialist clinics that appear counter to longer term goals with potential to undermine it on a number of fronts. Tensions such as these, many of which revolve around issues of specialist v generic, long term v short term, choice v needs, run throughout disability policies, but their recognition may avoid the abandonment or condemnation of shorter term or complementary strategies that are key to the immediate rather than future realisation of outcomes for individuals.
Exposing and Testing Assumptions

The problem of intellectual disability has been conceptualised in many different ways, but the State Plan appears to rely on a rights and social model perspective, which, despite its more recent reformulations, writers such as Sherry (2002) suggest tends to marginalise impairment specific concerns. This perspective tends to downplay the need for specialist medical, psychological, social knowledge about impairment privileging human rights and the individual’s expressed needs and choice. However, the World Heath Organisation’s International Classification of Functioning (2001) model suggests the coexistence of three perspectives, – capacity – activity and participation- which can be viewed as complementary rather than conflicting. Each perspective illuminates a different strategic lens for achieving broad policy goals of inclusion. Incorporating a broader theoretical perspective into the assumptions of the State Plan may give more breadth to the strategies available to enable issues associated with capacity and impairment, and activity limitations as well as rights and participation to be tackled, and greater acknowledgment whilst not privileging the contribution of specialist professional knowledge.

An important shift that has occurred in the State Plan has been the adoption of a dedifferentiated approach to broad disability policy. The underlying reasoning for this is difficult to locate but drivers may be the nature of the Commonwealth State and Territory Disability Agreement, and the dominance of an individualised perspective. The former gives pre-eminence to individuals and their needs rather than a structural perspective and accords lesser importance to more generic understandings about needs that can be derived from knowing the diagnostic group to which an individual might belong. Policies focussed on diagnostic group can be exclusionary for those at the margins, and assume in group homogeneity where it does not exist (Gates, 2001). An all disability approach may also be seen as more aligned with end of goals of inclusion and acceptance of difference. It may also reap the benefits of support from other minority groups such as the aged, for whom inclusive policies may be beneficial. It might be important however to make explicit and test assumptions that underpin the all disability approach, and perhaps adopt a contingency perspective for implementation strategies that considers, whether, at what level of implementation or in respect of what areas of policy more specific strategies for specific groups may be required? There is very little knowledge to inform key questions such as to ‘how should strategies to implement policy that

The Absence of Strong Causal Theories

Many implementation theorists suggest the underlying assumptions of a policy and the strength of the causal theories it relies upon should inform the implementation process. Drawing on work of Matland (1995) deLeon and deLeon (2002) suggest that policies about which there is low conflict and general agreement about their value but a high degree of ambiguity and uncertainty as to how the problem might be tackled require experimental approaches rather than highly structured and rigid programmatic strategies administered through government bureaucracy. Hoppe et al. coined the term ‘wicked’ to refer to problems that are ill defined, intractable and about which little is known as to how they might be successfully tackled (1987, cited in Winter, 1990). It seems that disability is one such problem, as it can be argued that there is little strong causal theory that underpins policy. Support for this view, and the need for a more flexible less structured approach to implementation is found in the evaluation of the first Commonwealth State Disability Agreement which criticised the rigidity of the administrative framework and standards imposed by the very top down approach adopted which obstructed an agenda of innovation and change (Yeatman 1996).

deLeon & deLeon’s (2002) proposition about experimental implementation strategies suggests the importance of making explicit the assumptions and theory that unpin policy to enable these to be built into and tested through different strategies and programs. The State Plan rests on a strong value base and set of philosophical principles that are underpinned by a broadly social model of disability. The policy recognises that deinstitutionalisation and community presence are a prerequisite for participation and inclusion, as closure of Kew Residential Services is a central strategy (DHS, 2002). However, like disability policies elsewhere the policy is hampered by the absence of one causal theory to inform achievement of community inclusion and participation. The social model of disability asserts the need for change to social processes and structures to enable inclusion of people with disabilities however the more explicit theory of how this might be effected for all groups of people with disabilities in all aspects of society has yet to be found. The absence of one overarching casual theory however does not mean there are not well researched or substantial bodies of knowledge around particular aspects of the policy for particular sub groups, that can inform implementation strategies. Rather it means there remain multiple means of achieving similar ends, uncertainty about which is most effective means, and indeed whether multiple rather than single strategies are required.
seeks to include people with disabilities in the
general community be differentiated to ensure
the very different needs of groups of people with
different disabilities are taken into account’. For
example, to what extent do the strategies required
to achieve inclusive public transport, inclusive
public services or inclusive participation in policy
making need to be different for people with
intellectual disabilities compared to that required
for example for people with sensory or physical
disabilities.

It may be useful, for example, to examine
the assumptions underlying the UK policy,
Valuing People that focuses solely on people
with intellectual disabilities but which is much
more narrowly focussed, than the State Plan on
service development and support to individuals.
Possible explanations for this differentiated
approach may be the very different issues that
arise around processes and practices required
to support choice, inclusion, participation
and representation for people with cognitive
impairment compared to those with physical
impairments alone. In trying to understand
the extent to which differentiated strategies
are required it may also be useful to examine
the outcomes of policies that have sought to
bring about structural changes for all people
with disabilities. The critique by Goggin and
Newell 2005 of Action Plans required by the 1992
Disability Discrimination Act for example may be
useful in informing the detailed implementation
strategies for the now mandated Disability Action
Plans for State government departments. These
commentators criticise Action Plans mandated
under the DDA as being too vague and generic
and simply reproducing common stereotypes of
people with disabilities as wheelchair bound, and
failing to address the less visible disabilities of
people with intellectual or psychiatric disabilities.
Innes (2006) too talks about the variable quality
and value of action plans. Such views are
supported by the report by the Productivity
Commission (2004) on implementation of the
DDA which points to the differential impact of
undifferentiated implementation strategies
adopted, ‘people with intellectual or psychiatric
disabilities have not have the same clear benefits
of people with physical and sensory disabilities’
(p. 38). A brief survey of disability advisory
committees established in Victorian local
governments suggest only a minority include
people with intellectual disability as members
yet this group is perhaps the largest group who
are potential but currently excluded users of
mainstream community programs and facilities
(Frawley, 2006). Outcomes such as these whilst
not conclusive suggest the need to carefully
consider the assumptions underlying policy and
the need for differentiated sub policy goals
and strategies, in order to avoid the pitfalls of
treating everyone the same and thereby ignoring
their very different needs.

Another assumption underlying the state
disability plan is the value of community, and
that by building social capital local solutions can
be found to problems such as social exclusion and
marginalisation. Few examples are found either
before or after the industrial revolution where
people with severe disabilities occupied valued
social roles in the community or experienced
life outcomes similar to the general population.
Reference back to the broader markers of socio-
economic markers of social exclusion earlier in
this paper however raises questions about the
veracity of local initiatives to solve broader more
structural factors that cause the marginalisation
of minority groups which have been explored in
the critical community development literature
since the late 1970s (Bryson & Mowbray 1981,

Questions too may be asked about assumptions
made in policy that the power to solve problems
such as social isolation and community
exclusion lie within government. Much of the
vision encapsulated in disability policy requires
significant change not only to community
attitudes about difference and disability but also
in the individual social networks of community
members so they become more inclusive of people
with disabilities. Reinders (2002) comments that
changes such as this are impossible to mandate
in the same way as rights or access to facilities
and services, and lie beyond the power of
government to implement.

A contrasting area is in relation to individuals
with disability, and assumptions about the
unfettered capacity of adults with disabilities
to articulate their own aspirations, wants and
needs and the availability and support of
family members in pursuing these. The broad
policy vision gives little recognition, and as a
consequence little attention to the alternative and
more complex avenues by which preferences and
needs may be ascertained for those with limited
capacity to communicate, or for whom family or
other informal support may be absent or their
views or needs might conflict with those of the
person with a disability. Such assumptions mask
the differentiated population of people with
disabilities even within diagnostic groupings
and obscure the need for a range of contingent
processes and strategies to take account to
differentiated situations.
The Policy Context

One of the four variables in Winter’s (1990) theoretical framework that affects implementation is the social economic context of the policy. Aspects such as resources, relationship to other policies, the existing nature of the service system, changing priorities or conditions over time have also been highlighted by other writers (Gunn 1978 cited in Bridgman & Davies; Sabatier & Mazmanian 1979). However, consideration of the broader overarching context of disability policy, such as the current neo-liberal ideology and the transfer of risk from governments to individuals, which have the potential to undermine its collective and redistributive elements are beyond the scope of this paper. These issues have been more thoroughly explored in the general social policy literature (see for example, Jordan 2000; Preistley 1999; Symonds & Kelly 1998; Sykes 2006; Alaszewski, Harrison & Manthorpe 1998).

Impact of Limited Resources

Many of the checklists that set out the conditions necessary for successful implementation include the issue of resources, who has control of these and whether they are commensurate to tasks required (Gunn 1978 cited in Bridgman & Davis, 2000). A common illustration of problematic resource allocation is found in the literature that is of the situation in the UK where the failure of some community care policies is suggested to lie in leaving responsibility for implementation of Central Government policies to Local Government without the allocation of specific resources (Symonds & Kelly 1998). In an early UK article on the implementation of intellectual disability policy, Hardy, Wistow and Rhodes (1991) draw attention to the importance of control over existing resources, by illustrating the impact that the professional autonomy accorded to the medical profession in the acute health sector, had in undermining policy that sought to shift resources and thus services from the hospital to the community sector. It is worth reflecting that half the current State budget for disability (DHS 2006) services is devoted to provision of supported shared accommodation, which raises for debate whether a long term goal is to shift resources from this to other models or to continue the process of improving practice in what may be an important model for many years to come. Either way the context of disability policy is such that significant resources are already allocated to an infrastructure of services, which means the strategic use of existing as well as new resources is a critical part of policy implementation.

The abundant estimates of unmet need within the disability sector leave little doubt about shortfall of resources to implement disability policy. Unlike the field of income support for example, disability policy gives individuals few enforceable legal entitlements, and the lack of indicators such as planning benchmarks found in other fields such as aged care mean people with disabilities have few clear expectations about the level of support or service that might be reasonably expected. At the same time as the broader political question of why there is such a shortfall of resources is addressed, (and the question remains whose task it this?) the implementation processes must take resource constraints into account to avoid policy objectives from being undermined.

Strategies for dealing with resource shortfalls may be the use of population based targets or benchmarks for service delivery so clear expectations are set and shortfalls are enunciated. Strategic decisions may need to be taken and advertised around the aspects of policy that will take priority, those that are less important or areas where standards may be suboptimal. By doing this, the situation is made much clearer, expectations may be readjusted and opportunity will exist for priorities to be challenged and realigned. For example, in Home and Community Care policy several years a go clear decisions were made around lowering the floor of service provision based on the rationale ensuring a large number of people had access to a little bit of service would better achieve policy goals, that smaller number of peoples having access to lot of service (Howe 1994). Such clearly articulated strategic decisions, about the use of resources are rarely found in the disability sector today. Such a process was begin in the early 1990s, when resources were cut to the sector, with public discussion of key priorities and core business of policy implementation, but such discussion does not seem to have been pursued, in the public domain at least (Cleave 1993). Rather an all too rosy picture of success if often painted which only serves to further disillusion those who are still waiting for support (see for example, DHS 2006; Bigby 2004)

If priorities are not explicit or strategies put in place to manage unmet demand this can interfere with all aspects of policy implementation and undermine the achievement of outcomes across the board. For example, the shortfall of places in supported accommodation may compromise the quality of support and application of underlying principles for those residents who do have a place, by vacancies being filled based on urgency of those waiting rather than choice by residents or optimal compatibility, or existing residents may be relocated within the system to create vacancies suitable for those with urgent needs. The use of larger shared supported accommodation for
older residents to enable the provision of day
time support and other more specialist health
related needs may compromise opportunities
for individual choice of lifestyle or participation
in both home and community. Other examples
where unmet needs can compromise service
quality are the erosion of preventative aspects of
service provision, such as use of respite places for
homeless clients, or diversion of individualised
planning from proactively considering the future
of those nearing transition points in their lives to
dealing with those in crisis situations. Also if the
management of shortfalls is left to frontline staff
significant discretionary powers are likely to be
vested in professionals to ration resources and
define the needs that are met, which inevitably,
though often invisibly, diminishes the capacity
for those seeking services to define their own
needs. Gate-keeping, rationing and managing
demand will inevitably divert frontline staff from
the core tasks of enabling individualised support.
Acknowledging and planning for unmet demand
must be an explicit part of implementation to
ensure the principles embedded in policy are not
overridden by resource issues.

Congruence and Conflict with
Other Policies

Significant congruence exists between disability
policy and other state government social policy,
both in terms of the focus on development of
community cohesion and inclusion but also in
relation to a whole of government cross
sectorial approach to implementation. For
example, two of the important issues identified
by ‘Growing Victoria Together,’ the medium
term policy framework for the public sector, are
building cohesive communities and reducing
inequalities, and promoting rights and respecting
diversity (Government of Victoria 2001). The
indicators around these broad goals are clearly
complementary to Disability policy and include the
extent and diversity of participation in community
cultural and recreational organisations, decreased
inequalities in health, education and wellbeing
between communities, having more people to
turn to for support in a crisis.

The congruency with broader social policy
will have a potentially beneficial impact on the
implementation of disability policy, in respect
of it being accorded priority by government
departments. It may also hold possibilities for
embedding implementation of disability policy
into broader strategies adopted as part of
community building and addressing inequality by
instrumentalities such as the Victorian Department
of Communities and Local Government. For
example, it may be feasible to build into the
mandated responsibilities for Local Government
to formulate Community Plans requirements that
attention to disability specific issues be reflected
in such plans and their administrative structures.
Such an approach may be more successful in
achieving long term structural change within Local
Government than shorter term programmatic
funding that generates activities but is not
sustainable without funds.

Commentators suggest that in regard to
broader public policy implementation the State
government is seeking to shift from programmatic
approaches to a greater emphasis on cross sector
implementation collaboration based on ideas
about network governance and the importance of
a spatial perspective (Adams & Wiseman 2005). It
seems likely too that disability policy will benefit
from these new strategic approaches being tested
and the cross government linkages being forged
as part of the new ways of doing business by
State government in other policy spheres. For
example Adams and Wiseman (2005) suggests
that a shift is occurring from implementation
based on rational top down planning and goal
setting accompanied by contracted delivery to
a more flexible approach based on coordinating
and connecting multiple sources of knowledge,
experience and expertise. Such an approach is a
good fit with the nature of disability policy and
the multiple systems it is seeking to influence.
This suggests that government experimentation
with implementation strategies that expand its
role beyond that of planner and purchaser to
include those of catalyst, developer provider,
enabler and broker purchaser, contractor will be
important in informing those strategies required
in disability policy.

Countering this congruency however, is the
actual or potential conflict between disability
policy and other policy directions of the
Federal Government or other State Government
Departments, which hinders and obstructs
policy implementation. The area with which I
am most familiar is the conflicting views about
which sector and level of government should
take responsibility for supporting people with a
lifelong disability as they age (Bigby 2004b; Bigby
2006). A further example is the often unintended
discrimination against people with disabilities
that occurs in other policies, such as the failure
of the Aged Care legislation to acknowledge
the premature aging of some groups of people
with disabilities. Sherry (2002) suggests a more
fundamental conflict is occurring between the
State and Federal Disability policies where an
individualistic medical model appears to be
reflected in Federal Government policy with
significantly reduced attention to human rights
and anti discrimination approach.
Inter and Intra Organisational Issues

A third aspect of Winter’s (1990) framework for analysing factors that affect implementation is inter and intra organisational issues. From an understanding of the nature of disability policy, it is very clear that implementation will rely on the cooperation and action of an elaborately complex network of organisations, including State and Federal Government Departments, Local Government, Non Government Organisations as well as the lead State agency the Department of Human Services. Ryan (1999) suggests that such organisations on which reliance is placed for action can be broken into policy subsystems, which are likely to be independent of the organisation that has main carriage of the policy, and will have their own interests and priorities. He suggests that key tasks of implementation will be to gain the cooperation, understanding and support for the policy of each sub system.

The more traditional top down theorists warn of the difficulties likely to be encountered where the chain of implementation is too long, and multiple players are involved in the processes of implementation (Bridgman & Davis 2000). They suggest the fewer agencies and potential veto points the less chance for misunderstanding and policy slippage to occur. This type of advice may only be relevant when implementation is through programmatic strategies, characterised by tight formulation of goals, specification of means and control over all aspects by a centralised authority. Ryan (1999) suggests, that it fails to take into account the uncertainty of inter or intra organisational relationships or the power of the actors involved to influence and shape what occurs. In his view, the adoption of a more fluid approach is required that involves other sub systems in implementation of the policy agenda through processes of bargaining and negotiation. By this means organisations have the opportunity to work out processes for implementation that are commensurate with their own structures. Essentially this means whilst goals may be specified the means should be left to those nearer the front line, be this in service delivery or planning procedures to develop.

The approach suggested here is also reflective of the more flexible experimental approach identified as necessary in an earlier section on the basis of the evolving nature of disability policy and its lack of strong theories of cause and effect in this field. It also echoes the suggestion of Adams and Wiseman (2005) regarding the new approaches to public administration by government that involve policy networks and extend its role from that of contractor or purchaser to broker or enabler. It suggests that implementation of Disability policy will require partnerships with other organisations that leave them relatively unencumbered to develop their own strategies around broad goals, rather than a more straightforward contractual relationship where inputs and processes as well as expected outputs are specified. This suggests a key task of implementation is the development of ways to measure and monitor outcomes rather than processes to ensure they are in accordance with policy goals, whilst leaving the intricacies of developing good practice to those closer to the front line.

References


Organisational Strategies For Supporting Implementation

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Introduction

The issue is not ‘this is what we are here for. The issue is this is how we do it.’ (Drucker 2005)

There is no shortage of good intent in the disability sector. There is much debate about implementation and ‘what makes a real difference.’ There is agreement from all perspectives that ‘what makes a real difference’ depends on knowing the needs of each person with a disability and meeting those individual needs. The dilemma is often how to do it. The pattern has been to design programs, with funding and delivery specifications, for state-wide or nation-wide implementation, even when this involves individualised funding to people with a disability. This paper considers how the effectiveness of these programs – their outcomes for people with a disability - depends on emphasising and building the organisational capacity of each individual provider to be ready and capable to implement individual support arrangements.

The organisation delivering the program matters, regardless of the funding mechanism (for example, organisation block-funded, individualised for the person). Without attention to improving individual organisational capacity, an organisation’s ability to deliver programs is compromised thereby limiting the achievement of policy and goals at various levels or non government organisations’ mission statements. Programs are funded and then implemented differently by different organisations – but do we understand why? Funders in particular have an important role to understand the relationship between nurturing organisational capacity and ensuring effective program delivery.

An Organisation Should Be More Than The Sum Of Its Programs

Organisational identity

Building organisational capacity depends first on establishing organisational identity. Many older welfare, community service and disability organisations developed before government became more involved in funding, monitoring and steering social policies. These organisations, often with a religious base, usually have a strong sense of identity linked to a local community, social cause or disadvantaged group, and separate from government. They know they are more than what is currently funded and that their mission need not be identical with government policies. Commenting on government policy is an important aspect of their identity. Many smaller disability organisations, particularly community-based accommodation, employment, leisure and some day programs, were ‘created’ by government as institutions began to close and there was a need for community-based service delivery in the seventies and eighties (Lyons 2001). Given this history, their identity, separate from what government currently funds, has been more difficult for some to establish as the funding regime has determined the shape and priorities for the organisation. Doing what government funds by being an extension of government (in practice), but less costly, has become a way some non government organisations are viewed by government, and how some non government organisations view themselves (Lyons 2001). This is despite the potential for smaller organisations to develop strong identities and allegiances within their local communities and to foster less bureaucratic ways for service users to participate in each organisation.

Gap between design and delivery

Unlike research and development in other spheres, disability support programs are designed by one organisation and then expected to be delivered by many others with little understanding of this distributive process. Typically, a new program is designed by government and then distributed through submission or allocation to various providers, increasingly with direct funding to each person with a disability. Service providers have become deliverers of government pre-arranged programs and not experts and designers (Letts et al. 1999b). These design decisions are left to government, albeit with varying consultation processes, who then undertake planning and dispense funding for delivery. The danger in this approach is that service providers become less sensitive to interpreting policy and developing policies and practices which are better and go beyond what government can devise (Lyons 2001) for their local circumstances and target group. It can be debated whether this is creating a dynamic in this sector of government stipulating more and more in program development terms and service delivery organisations waiting more and more to be told.

Paradoxically, in practice there are many examples of service provider exceptions to implementation to what government specifications required.
Further, there have been examples of new programs being implemented with less defined specifications adopting a 'wait and see' approach from government to see how providers develop a new program. A review stage will follow with suggestions for uniformity. Given that these variations are often not reported, the question remains whether best use is made of the insights and learnings of service providers both within the provider organisation and more widely. There is very little discussion between providers about how programs are delivered. There are of course examples of innovation, research and pilot programs in this sector. There are however, few open forums for discussion of the learnings.

As design and implementation are often disconnected processes, resources are not routinely invested by, or available to, service providers in research and development to discover if there are superior ways to deliver services that are better for people being supported and more efficient for the organisation. In Victoria, there are limited links between research institutions and service delivery organisations. Without involvement in wider research and evaluation information, organisations are vulnerable to understanding their role as getting more programs and adding more programs to their organisation as soon as they are prescribed and funded by others.

If programs are simply added to the organisation as if all programs are independent, there is a loss of attention to overall organisational performance through a process of fragmentation or failure to consolidate. This process risks compromising the central core of a service delivery organisation as defined by its mission, the leadership vision is reduced and the core progressively contracts. Achieving government policy in practice becomes elusive. Achieving the wider goals of the organisation is similarly disrupted. Any service delivery organisation needs to be more than the sum of its programs if it is to be able to demonstrate effective and efficient performance to all of its interest groups. Examples of such consolidation are apparent as providers argue for a single approach to case management or individual planning, regardless of the source of the funding program. Other sectors do not name the program to be delivered or the funding source in this way. For example, a prospective patient is not informed how an operation is to be funded or what the current funding program is called. What the patient requires, the operation, is the main public focus for any discussions with the hospital.

Good Program Delivery Depends On Organisational Capacity Not Program Design

All hope is laid on the design of the program, not who is implementing it (Letts et al. 1999b).

Individual organisational capacity determines the ability of an organisation to undertake service delivery. This includes an organisation’s response to the systems and processes needed to support its mission or goals given the people being supported, the shape and history of the organisation and the community in which it is located.

Trends identified within not-for-profit literature, which can be tentatively extended to government providers, are that there is much less support available to disability sector managers compared with the business sector managers from industry whose boards and investors encourage them to take organisational capacity seriously. In the not for profit world, programs and organisational capacity are considered almost as competitors in a zero sum struggle for limited resources (Letts et al. 1999b).

The result is that individual disability providers may not be rewarded or encouraged for attending to organisational capacity or performance, as distinct from individual program delivery issues. Ironically this jeopardises what can be achieved in program delivery.

The programs that stand out are those which are well implemented. Performance not program design alone makes the difference. Innovative often means little more than well implemented (Letts et al. 1999b).

Given the demand for services and supports, various organisations, on behalf of people with a disability, are understandably pursuing more programs. Most organisations want ways to expand or extend program delivery. This leaves unconsidered and unanswered how any organisation actually delivers an effective program in the first place (Letts et al. 1999b), particularly given that the same program design may be funded across many organisations and with different results.

Examples of building organisational capacity include:

- building understanding of the values and goals for the organisation including within the Board, managers, supervisory and direct support staff and family and wider community members
- developing organisation-wide orientation and induction training relevant to the mission and values of the organisation and the people being supported
• on-going training which emphasises the technologies of support (such as Active Support, positive behavioural support, communication, quality of life) for the particular people being supported
• organising resources around the part of organisation which will achieve the goals of the organisation, that is around staff practice and front line management which determines how well each person is supported
• adoption of evidence-based and world’s best practice approaches
• internal research and measurement of performance including evidence for, and articulation of, current practice including leadership, practice coaching, periodic service reviews and reviews based on quality of life indicators.
• development of an organisational practice identity which is understood throughout the organisation
• measurement of organisational-wide outcomes against the organisational mission or goals, for example, in relation to promoting independence or empowerment
• sophisticated and supportive business systems which support, and do not undermine, direct support practice (for example, data gathering about implementation of individual plans).

It is the coherence and strength, or not, of these systems and use of resources within an organisation which optimise service delivery and within which new programs are ideally integrated and embedded. It is important to distinguish more generalised initiatives, such as sector-wide or pre-service training from the discussion about individual organisational capacity. While such directions may be important foundations or starters, they tend not to be adapted within a frame of each individual organisation. They are therefore limited in their contribution to building organisational culture, common purpose and commitment.

If improving organisational capacity becomes the priority, the central question actually becomes ‘how does each organisation perform well (to support people with a disability)?’ This means it becomes possible to consider program design and organisational performance together. A recent evaluation of day programs for older people with a disability (Bigby, Fyffe & McCubbery 2000) rated different types of organisations supporting older people with a disability against indicators of good program delivery for this age group. It was factors within organisations, such as management and leadership and individual planning systems, rather than the program design (such as, specialist programs for older people) which were most critical to good program delivery. The traditional day program was as successful as the apparently more ‘flexible and innovative’ arrangements. The challenge for the disability sector – providers, policy makers and funders is countering why individual organisational performance is such a low priority to be researched and enhanced. We constantly rely only on the design of the program to be delivered.

**Funding organisational capacity as a basis for better program delivery**

Organisational development processes currently attract little funding. Funding programs which only attend to direct service delivery components fundamentally ignore the importance of organisational capacity to achieving what the program intended. Funders – all levels of government, philanthropic, private -have not been sensitive to the need for developing organisational capacity as integral to effective program delivery. Any funding program which only considers direct support costs is ignoring the importance of organisational capacity and the contribution leadership, management, defined models of practice within the organisation, supervision, training, evaluation and so on to effective program delivery. This contributes to direct support staff not understanding or knowing how to carry out the intended programs, thereby reducing staff motivation and involvement in their central role within the organisation.

Typically government or philanthropic funders are interested in new programs. This encourages service delivery organisations to think of innovative programs but does not encourage them to assess their ability and needs as an organisation (Letts et al. 1999a). Programs funded across the state will flourish with some providers and not with others. Many organisations lack capacity to carry out the programs despite how well the program has been planned. It is the capacity of organisations to deliver and not the design of the programs which requires more scrutiny, assistance and development.

Service delivery organisations have a responsibility to keep the organisation healthy in terms of issues such as work force, operating systems and revenue into the future. Unfortunately, funders tend only to be interested in shorter time frames. Letts et al. (1999a) argues there is opportunity for philanthropic organisations particularly, but it applies to government funders as well, to change their roles from assessment before grants are made and then oversight, to a role to support development of capable management and organisational systems in each organisation that can deliver programs optimally. This leads to questions for funders such as whether their funding emphasises narrow program innovation at the exclusion of organisation building and performance based around achievement of mission; whether funding
organisations know what would be helpful to service delivery organisations to improve their performance and how they would find this out; and whether there is scope to fund in different ways, such as the venture capital approach from business development. The development of organisational capacity has been accepted by funders for self advocacy organisations (Fyffe et al. 2004) where it is recognised that failure to develop the organisations overall detracted from the effectiveness of self advocacy activities.

**Frugality Or Financial Management Is Not The Same As Good Performance**

*Many NGOs think that a hand-to-mouth existence is the natural order – sadly so do many government officials and members of the public* 

(Letts et al. 2000).

An example is the history of governments achieving productivity savings through not funding full cost of living adjustments and staff increments.

*Organisational development is viewed as an indulgence taking service from clients*

(Letts et al. 1999b).

*Low overheads .... so esteemed.... can signal not only frugality but also low performance*

(Letts et al. 1999b).

One of the effects of the push for increased government, predominantly financial, accountability in Victoria in the 90's is that there has been little development of reporting to other stakeholders, such as community members, Board members, people being supported and potential service users.

*Knowing whether and how much an organisation is in the black or the red does not speak at all to what the organisation is doing well, or whether and how it should be improved*

(Letts et al. 1999b)

How to measure performance of organisations beyond government financial reporting has proved elusive. The most important measure of success is the achievement of mission-related objectives and not financial wealth or stability of the organisation (Dees 1999). In the absence of attention to organisational performance, the disability sector risks organisational thriftiness being equated with good organisational performance. Improving organisational capacity is often understood as taking resources away from service delivery and the benefits for those being supported. Funders often put organisational capacity into the same category as administrative overheads (that is costs which divert resources from the ‘real’ work of delivering programs), and such overheads should be minimised. This contributes to why many organisations are chronically under funded (and perhaps ‘under-aware’) regarding organisational capacity and ‘hide’ their requirements for organisational capacity within funding applications or simply don’t apply for programs without this component. The consequence is that programs can be delivered with low cost or balanced budgets being the only indicators of successful implementation. This is very attractive for funders wanting to reduce costs. It should be very unsatisfactory for funders and other stakeholder groups when it is in the absence of indicators of service quality and outcomes for individuals with a disability.

Attending to finances says nothing about achievement, innovation or quality of sustained performance (Drucker 2005; Letts et al. 1999b). There is a need for new ways of linking funding to organisational performance (Dees 1999). Currently there is little analysis of what happens for people with a disability as measured against missions or policy statements. Each organisation needs to define indicators of its effective performance, among other purposes, as a basis for application to funders. The complexity of devising such social measures shouldn’t be reason to limit their pursuit.

**Organisational Performance Linked To Organisational Goals And Objective Outcomes For Service Users Not Programs**

The disability sector is replete with ideology, ideas and aspirational policy. The mission or policy statements of organisations providing services to people with a disability are ambitious and extend well beyond service delivery. The aim is often to rectify or achieve a social or cultural change. This foundation is not reliably converted into effective achievements and changes for the people receiving services. The disability sector tends not to give priority to performance, strategy and results (Drucker 2005; Rangan et al. 1999).

*‘Faced with a choice of doing or analysing – most human service organisations go for doing’*

(Letts et al 1999b).

Service provider organisations have various (potential) roles and consequently various interest groups. Both government and non government organisations have roles including advocacy, community development or capacity building and various service and support responses. Accountability for performance is needed for all of these roles. That is, people receiving services and supports, people wanting services and supports, people within the organisation (staff, Board, members), the community, funders including government and philanthropy and regulatory groups. The separation of funder
and service user means the usual market client satisfaction measure is not a guide to organisations in the same way as traditional market place (Herzingler 1999b). In the era of promoting choice for people with a disability, if there is little (public) information about the performance of organisations, it is difficult to understand how potential service users truly choose a support organisation and what it is they are choosing.

Lack of attention to organisational performance as measured against mission statements means the intent of these mission statements can be lost (Herzingler 1999b). Without information all stakeholders, including the public, cannot know if an organisation is fulfilling its mission. Measurement should include the quantity and quality of services provided in terms of the implications or outcomes for each person with a disability. Some form of sanction is needed for poor performance inconsistent with mission or policy. For example, how can organisations make decisions which exclude people with the highest support needs or justify the assignment of high needs groups to more conservative support models? However, attention to such indicators would also highlight when the available funding does not allow the achievement of the organisation’s mission, for example, when care, safety and constraint is the only possibility for an organisation which measures its performance against quality of life indicators. Who provides such funding may be another debate, but identifying the issues allows for clearer debate and development of all possibilities.

Strategies which contribute to organisational performance being able to be more widely reported include:

- making the risk of poor service responses a management (and Board) issue
- building a culture whereby staff performance is judged by service delivery implementation and outcomes for each person with a disability
- ensuring what was planned for each person being support happened
- describing how the community’s members with the highest support needs have always been included
- reviewing organisational decisions which have major life decisions for people with a disability such as withdrawal of service or more restrictive support options
- promoting work place safety for the support role required of staff
- noting the risk to the individual of not being supported to do a preferred activity
- specialising and being a resource for others.

A similar comment can be made about organisational performance relevant to the community:

> It is nonsensical for organisations to claim to be linked to the community or community-managed organisations when they seek little or no support from the community or do little or nothing to report to that community on their activities and plans

(Lyons 2001).

For example, accountability to the local community could include:

- how community members have contributed to inclusion of people being supported
- how many community members are wanting services thereby making waiting lists a public issue
- looking for ways to identify those not in services
- commenting on government policy and relevance for a specific community or target group of people
- overcoming sector barriers and planning with related providers at local level particularly aged care and HACC as well as business and community providers
- developing local funding initiatives across private, business and community sectors.

Initiatives where organisations consider their performance against disability standards have been a start. However, standards tend to look at minimum performance across a sector; they do not identify how well an organisation is responding to its specific service users. More relevant frameworks adopt a measurement of results approach (Schalock et al. in press).

> How do we define each organisation’s performance, consider what sort of person are we trying to produce? For example, achieve personal goals, become a participating citizen within the economy, and cultural life of society. How are these gains best measured?

(Drucker 2005).

Measures to be explored could relate to independence, having a productive and purposeful life, being part of the community and quality of life of families. These measures would apply regardless of the funded programs being delivered, how the organisation is structured and who are the recipients. Each service delivery organisation needs its own systems of measurement and review. This means deciding what matters most for this organisation given its policies and mission and ensuring initiatives around what matters most across all activities and programs (Herzingler 1999b; Taylor et al. 1999). For disability support services this suggests a major investment in direct support and front line management activities.
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Roundtable on Intellectual Disability Policy
Resources, Regulation and Risk

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Introduction
The scale of the task of achieving equal rights and opportunities for people with severe intellectual disabilities is formidable. Intellectual impairments, often coupled with other serious problems, are among the most pervasive, serious and complex that occur. They have a devastating impact on the individual and their family. Despite important advances in prevention (for example of phenylketonuria and iodine deficiency) and treatment (for example developmental education and programming) a small but significant proportion of the population will need substantial extra support throughout their lives.

There is no shortage of ideas as to how to provide this support. Reacting to the legacy of eugenics policy and appalling deprivation in institutional care, intellectual disability has been an area which has seen some of the best thinking and best practice about models of supporting people with serious disabilities. It is a field in a constant ferment of experimentation and struggle. Deinstitutionalisation, group homes, staffed housing, supported living, supported employment, individual programme planning, person-centred planning, total communication, positive behaviour support and person-centred active support are all important contributions to creating a better life for people with intellectual disabilities.

It is, however, the argument of this paper that the innovation and creativity which has been a characteristic of the field of intellectual disability for fifty years is under threat and requires protection. This threat does not come from within the field – not from intellectual disability nor from the wider disability movement. It comes from processes at work generally in public policy. The first of these is economic – it is the dominance of cost as a criterion for policy action and the importance of economising wherever possible that threatens progress. Cost constraints have of course been a constant companion in disability services – the scandals in institutions in the nineteen-sixties and seventies had their roots in overcrowding and understaffing and a sense of inevitability that this was to be the norm. What is new for the intellectual disability movement now is the sense of a sea-change in public policy that might take us back to abandoned models of care. The second process impinging on intellectual disability is the growth of regulation across the public sector as a means of influencing practice where services meet the people using them. Dissatisfaction with ‘delivery’ – both by public organisations (government departments and their agents) and individual professionals - has led to much greater attempts by government to direct practice. The third process to be addressed in this paper is the growth of risk as an issue in public policy and what might be called ‘the risk management of everything’ (Power 2004).

These three are all expressions of the ‘new managerialism’ in public services (Exworthy & Halford 1999), itself part of the wider neoliberal revival in Anglo-Saxon countries since the end of the nineteen-seventies. It is important to acknowledge that these forces, as applied to public services, have a positive purpose. Dissatisfaction with waste or ineffectiveness in public services is commonplace. Governments have chosen to restrain spending, give more detailed direction and focus on risk because they believe that this will improve things. However, in this as in many areas of human action, the Law of Unintended Consequences (Merton 1936) applies.

Resources
Public expenditure on health and disability in Western countries is rising. The largest components of increasing costs are those associated with (i) an ageing population, (ii) lifestyle-related problems such as diabetes, smoking and obesity and (iii) better healthcare technology (OECD 2006). In some countries (such as the UK), there has also been a shift from unemployment to disability benefits (Berthoud 1998). These changes have produced a sense of panic as governments face the prospect of rising costs and they have prompted debate about the future role of public expenditure in meeting these costs (OECD 2003).

However, these issues have little to do with severe disability, or particularly with intellectual disability. Here the numbers of people are not increasing dramatically. Bettersurvival, due largely to offering disabled people the same standard of health care as the rest of the population together with improvements in medicine and care, has increased the number of people with intellectual disabilities but more widespread detection and termination has tended to reduce it. Changes in the age structure of the population also lead to increased numbers. Overall, recent English research (Emerson & Hatton 2004) suggests an annual increase of under 1% in the number of people known to intellectual disability services in the period 2001-2021; including everyone whether, known to services or not, the increase is approximately 2% per year.
Likely need for services is increasing faster than this. Aside from aspirations about equality of opportunity, if the same proportion of people get accommodation, increasing average age is likely to require out-of-home residential support in England for an additional 12000 adults with intellectual disabilities by 2011 and for an additional 20000 by 2021. This is an annual increase of about one-fiftieth the existing volume of service, in the eighth richest country in the world.

These modest increases are real: they reflect extra numbers of people who were not there before. Meeting even these needs has provided difficult for governments. There is evidence in Australia and the UK of reducing service quality by funding larger residential homes and an attempt to re-open the argument that institutions might not be so bad after all (Bigby 2004; Care Principles 2004; Cummins & Lau 2004; Emerson 2004a, 2004b; NSW Government 2005; St Luke’s Hospital 2004). Since there is no evidence at all that larger services are better for people (and actually good reason and some evidence to believe they are worse) this is presumably an attempt to stretch existing funds to make them cover more people. How then will governments respond to the policy goal of improving services – of extending services to people who have not hitherto had them (meeting unmet need) and to improving the quality of service by, for example, providing more staff support to people with the most severe intellectual disabilities?

It is critically important for those defending disability services to recognise that these are not extra or new costs. Costs associated with quality of service fall mainly on three groups of people: the disabled person, their family and friends, and the public through taxation and service provision. For the person with severe or profound intellectual disabilities themselves, they pay some of the costs of their disability through poverty, shorter life, poorer health and lower quality of life in almost any respect that can be measured. For the family and friends of the person (which for most practical purposes means above all their mother), they pay through the foregone opportunities, including earning power and standard of living, the stress and reduced quality of life that they experience. For the public, they pay through making marginal adjustments to how they live their lives and through paying taxes. Evidence about the relative contribution of these three partners in payment seems scarce, but it is surely beyond doubt that the costs to disabled people and their families far out-weigh any cost to the public purse.

If governments pursue a policy of holding total expenditure constant, given growth in the number of people needing support, they are reducing the amount of funding support to disabled people and their families. They are therefore transferring back to people costs which were once met, albeit to a very limited degree, by the whole community. Distinguishing this from the much broader picture outlined at the beginning of this section might be a very important contribution to renewing and revitalising the debate about expenditure in disability services.

**Regulation**

Greater regulation reflects two different but related forces at work in public administration. First, a long history of systemic failures and professional incompetence has fed a concern for greater accountability. Elected representatives and those who speak for the public want evidence that services are being delivered as they should be. They no longer trust the professional to use their judgment and to do their best for the individual they serve (in Le Grand’s (2003) terms the knights have become knaves); they no longer expect public authorities to act responsibly (Bristol Royal Infirmary Inquiry 2001). Second, despite an incontinent appetite for structural reorganisation (at least in the UK), there are signs that government has listened to researchers who point out that what really makes the difference for people using public services is how the staff they deal with (teachers, social workers, doctors) treat them. That is, that quality of service depends crucially on what front-line workers do. Government has, therefore, got into the business of dictating what front-line workers should do.

In doing this, government has fallen into a common trap. Desiring influence and evidence, it has sought to measure what can be measured and to prescribe what people should do rather than what they should achieve (Gilbert 1978). Thus, for example, the English Care Standards Act prescribes 43 standards relating to accommodation, staffing and processes in residential homes for people with intellectual disabilities (Department of Health 2002); recent research suggests that whatever these things measure, it is not the lived experience of the residents (Beadle-Brown, Hutchinson & Mansell 2005). The connection between process and outcome has been broken. One of these standards entails the production of a menu, displayed publicly in the home, to demonstrate that residents get a wholesome diet. What residents with severe disabilities actually eat depends on the degree of organisation of their direct-care staff (did anyone remember to do the shopping?), their cooking skills (or shall we have a take-away tonight?) and the quality of support to people who need help eating (don’t you want...
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It forces a shift towards direct observation and extent to which regulation can rely on paperwork. An outcome focus imposes great limitations on the process, not the menu but the meal. However, the criterion is not the process but the detection. So ensuring proper process is important. What would regulation in intellectual disability services look like if it was based on these principles? First, it would be strongly outcome-focused. Given the goals of independence, social inclusion and choice (or any other set of outcomes which work) the regulation would be focused on the extent to which they were achieved and safeguarded. This doesn’t only mean looking at outcomes. Consider abuse; the goal is that it should occur rarely through good prevention and detection. So ensuring proper process is important. However, the criterion is not the process but the outcome; not the menu but the meal.

An outcome focus imposes great limitations on the extent to which regulation can rely on paperwork. It forces a shift towards direct observation and experience. Staff in services often work in relatively unassisted situations, have wide latitude and have to exercise considerable judgment in their work. Research among residential care workers in intellectual disability services shows 40-50% say that their co-workers or managers will not notice or take action if they fail to work appropriately with residents (Mansell & Elliott 2001). As a first step, someone other than the service user (who may not in any case be able to voice their concerns) needs to notice whether things are going well or badly.

Second, regulation would be one tool in the box, not the only tool in the box. In particular, consideration would be given to why people don’t do what is desired. The belief that no-one will notice is important, but it is not the only factor. The promotion of a strong sense of professional values (‘doing the right thing’) as a means of self-monitoring is probably important in these circumstances. The extent to which people perceive that their managers are really interested in and committed to the values the organisation espouses is also likely to be important. Regulation complements quality assurance as part of organisational capacity – it can’t replace it.

Risk

Probably the most intrusive example of regulation in disabled people’s lives is occupational health and safety and the culture of risk management. Services are replete with examples where health and safety requirements take precedence over quality of life. There is beginning to be a well-developed critique of risk management culture and its main tenets are clear (Baldwin, Hutter & Rothstein 2000; Power 2004):

- Risks are constructed: that is, some things are defined as risks in particular ways, while other things are overlooked. For example, the risk of extended inactivity or being cooped-up all day to a person with intellectual disability may not be considered, but the risk of their challenging behaviour to the member of staff going shopping with them will be. Generally, risk management in human services seems to emphasise risks to employees and reputational risk to organisations rather than risks to service users or their families; and immediate rather than long-term risks.
- There is an important division between people who think risks can be identified, assessed and predicted accurately and those who argue that this is often not possible and that risks have to be negotiated and managed. The typically heavy investment in assessment and prediction at the expense of capability and
responsiveness is questioned, as is the balance between low-probability events which are difficult to predict and the effect of precaution on everyday life.

• Blaming people when things go wrong may lead to an excessively individualised analysis, so that systemic failures are not picked up.

• Compliance may be influenced by many factors including self-interest; the benefits of breaking the rules and running risks; an organisation’s feeling of responsibility, public accountability and reputation; the likelihood of detection; level of knowledge or of the risks; competing organisational objectives and costs.

• Achieving compliance may not produce the results that policy-makers desire. People may focus on what is measured rather than on the risk itself. There may be unintended consequences.

• Professional judgement presents special problems for command-based régimes, because professionals often make decisions and policies that are of high importance, low visibility and high discretion. They also tend to protect their ability to make decisions and to resist control, especially if they doubt the motives or competence of those proposing the rules. For professionals, therefore, risk management should emphasise ‘openness, peer group scrutiny, incentive structures, training, cultural contexts and collective as well as self-appraisal approaches, rather than reliance on external rules and blame-based régimes’ (Baldwin, Hutter & Rothstein 2000).

Victoria may posses a uniquely draconian system of health and safety regulation in that the link with insurance (‘Workcover’) creates powerful incentives to abide by the rules even where this has the unintended consequences of poorer quality of life for residents. However, even in this situation it is important to note that the risk regulator is realistic. The Occupational Health and Safety Act 2004 includes as a key principle ‘Persons who control or manage matters that give rise or may give rise to risks to health or safety are responsible for eliminating or reducing those risks so far as is reasonably practicable’ (emphasis supplied). The regulator recognises that not all risks can be eliminated.

If the regulator acknowledges the possibility, why is health and safety such a serious problem in the daily life of people using services? This is surely a problem of ‘street-level bureaucracy’ (Lipsky 1980). The practicalities of decision-making are negotiated between front-line workers and managers in services and front-line personnel of the regulatory agency. In a blaming culture, the tendency is to err on the side of caution, even if that means impairing someone’s quality of life.

Conclusion

These three factors external to the sector are already beginning to undermine the vision of individualised support for disabled people which enables them to live as independently, with as much choice and as much part of the community as possible. They are very powerful forces having an impact across all public policy; they cannot be ignored and they will not be easy to resist. The question therefore is how to engage with them?

What is perhaps most striking about the sector’s response is what is missing. There appears to be no clear critique of what is happening, no statement of the principles that should apply to allocating resources, regulating services and managing risk in a way that supports the policy goal for disabled people. The sector is strong on vision but not on naming and addressing these threats. Instead, responding to these forces is largely left to individual service providing organisations, to managers and to staff. But these are not forces that can be reckoned with at street-level.

Nor can effective response be left to government. Supports of disability rights within government can advocate for change but they are unlikely to be seen as sufficiently powerful to compete for attention and agreement unless they are backed by a well-organised and vocal sector.

‘All that is necessary for the triumph of evil is that good men do nothing’ (Burke). Why is it that, faced with these threats to a hard-won policy, the sector is silent?

One argument might be that government, in funding services and the network of organisations that represent and provide them, censors them. If this is true then the choice may be between gradually succumbing to the threats, isolated and alone, until services have lost any sense of the vision; or banding together to start arguing the case now.

A second argument might be that perhaps the sector is too exhausted and disorganised to respond effectively. Despite the existence of peak organisations and a thriving field of organisations representing user and service interests, perhaps no-one has the time or energy to organise. In this case too finding the energy may be easier now than in the future.

Third, perhaps the sector is ashamed of its own achievements – that it feels vulnerable to the charge of inefficiency and waste. Commentators have certainly pointed out that new models of community service replacing institutions have not really lived up to the promise either of the vision or of the early demonstration projects (Mansell 1996). However, there is no evidence that other models of care are more efficient; institutions
are cheaper because they provide each person with less staff support not because they do more with less. Again, there is evidence that well-run community services do provide added value (Mansell, McGill & Emerson 2001). So there is no need for disabled people and those who serve them to be apologetic about their achievements. It would be sensible to pay attention to getting the most out of new service models, to be able to demonstrate their evident quality to a sceptical audience, but this is part of the process of building a stronger sector, not a reason for abandoning it.

In all this, there may be a lesson from the past. The vision of a better life for people with intellectual disabilities, and the progress that has (however tentatively) been made towards it, depended on a social movement. This was a movement that brought people of good will together from across the wider community, from government, from the professions and from the families of people with intellectual disabilities themselves. It mapped out a new vision and new agenda for disability services. Then, as that agenda was accepted and taken on by government, the movement faded. Perhaps the lesson of these twenty years is that reform is not an automatic process that, once started, continues unguided. Perhaps it needs a head and a heart, to drive it forward in the way intended.

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