

Disability: Local, National and International Trends

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Abstract

People with disability are an extremely diverse group with diverse needs. Over the past 100 years people with all types of disability have moved from being commonly expected to be institutionalised in large facilities, to now being encouraged to participate in all aspects of society.

This change has occurred through major theories such as Social Role Valorisation showing how people with intellectual disability are devalued and should be given roles of value in society. It has also occurred by disability activists pointing to the barriers in society that cause disability. Most recently there has been a range of rights-based philosophies under the headings of 'independent living and inclusion'. These call for people with disability to be given control over their lives and make their own decisions. This movement wants people with disability to be treated as full citizens and the barriers in society which reinforce disability to be removed.

The current models and approaches to community engagement, support and services for people with disability are consistent with rights-based philosophy with community development and access for people with disability to mainstream services, a common theme. Person-centred planning and individualised funding in a variety of formats are the common tools used in current approaches to achieve the goal of independent living and inclusion for people with disability.

There are a range of issues which will impact on the future effective implementation of these models. Firstly, the extent to which a cultural shift occurs within government funded organisations. Secondly, issues such as the increase in ageing population, and the decrease in the support worker workforce, will impact who gets services and how they are structured. Thirdly, broader social and political change will affect the availability of resources for the disability sector and how a rights-based approach is implemented given the ratification by Australia of the UN Convention on the Rights of People with Disabilities. Finally, the federal and state systems and historical fragmentation of services will shape how change occurs.

Future trends, on the one hand, include the likelihood of more streamlined and flexible service systems, an increase in people with disability in mainstream services, and more individualised approaches using person-centred planning and individualised funding. It is likely that there will be less fragmentation and a bundling of programs and funding. On the other hand, there are also fears that workforce and resource issues are leading to possible mini-institutions with 10 bed group homes and cluster housing of 10-20 units which will further isolate and segregate people with disability.

Introduction and Scope

This paper examines local, national and international trends in approaches to community engagement, support and services to people with disabilities. The history and current status of various philosophical underpinnings will be outlined, contemporary current trends identified and analysed in terms of benefits, costs and key drivers. The possible impact on people with disabilities and service systems in Western Australia over the next 15-20 years will be examined.

History

The definition and understanding of disability and its impact on people has changed over time and has been influenced by theoretical discussions about disability. This has meant that often the term 'people with disability' is used when, in reality, it is the perspective of one group of people with disabilities that is being portrayed. This is particularly true when looking at the history of people with disability. However, there are also parallels between different groups of people with disability, for example, people with sensory impairments were institutionalised and segregated in special schools, while those with intellectual disabilities were put in institutions for the mentally ill. Activism from people with disability has come from groups of people with predominantly physical and sensory disabilities, while carer and parent groups have been active on behalf of people with intellectual disability.

Over the past 100 years the lives of people with disability and their engagement with the broader community has changed dramatically. Attached to this monograph is a timeline which gives an indication of significant events and developments, both internationally and nationally, that changed the lives of people with disability.

A brief summary of this history shows that over 100 years ago people with disabilities were most likely to be living with their families. Those with severe impairments would be unlikely to survive and those who experienced catastrophic injury also did not live long or were reliant on relatives to provide care. From the late 1800s people with intellectual disability, acquired brain injury, and multiple disabilities were highly likely to be put into institutions for the insane, or expected to be institutionalised. Parents were often advised that their children were ineducable and should be given up to institutions so they could continue their lives (Disability Services Commission, WA).

As time went on, fewer and fewer people with physical and mental disabilities were seen in public and the practice of segregating people with disabilities from the rest of society became the rule rather than the exception. By the early 1900s it was expected that a person with a physical or cognitive disability would be living in or attending an institution (The Minnesota Governors Council on Developmental Disability). A majority of people with disability still lived in their family home, however there was very little support for families apart from institutions.

Up until the 1960s and 70s there was a growth in large segregated institutions to accommodate, educate and provide daytime activity for people with disability.

From the 1950s there was strong development of parent groups who wanted to secure better opportunities for their sons and daughters. The focus in WA through the 1950s to 1970s was one of training. People with disabilities were living in institutions and attending day-institutions to receive training and develop skills to manage their disability (Disability Services Commission, WA).

There was also at this time a rising disability movement internationally with activists and groups of people with disability becoming more political in Europe, especially the UK, the USA and Canada. This was often led by people with physical disabilities who had acquired disability through war or through contracting diseases like polio. For people with intellectual disability, the principals of Normalisation and Social Role Valorisation (SRV) provided the basis for new types of service. This all led to deinstitutionalisation becoming the dominant factor driving service development for people with disability from the 1970s. (Young and Ashman 2004, 21-28). In WA, SRV was the driving force behind disability policy, and is still prominent in policy today.

Deinstitutionalisation in Australia was about 20 years behind what occurred in Europe and North America (Young and Ashman 2004, 21-28). Group homes, cluster housing and support in the family home have become the generally accepted ways of supporting people with disability in accommodation in the community. Many people with disabilities attend mainstream education, work in open or supported employment, and participate in community activities. Many also still work in business services (previously known as sheltered workshops), or attend disability specific day services or groups, and special schools.

It was only in the 1980s and 1990s culminating in the adoption of a broad definition of disability in the Disability Discrimination Act 1992 (DDA), that the definition of disability in State legislation has also been broadened to include a wide range of disabilities. It is important to understand the context where any definition of disability is used, for example the DDA is about discrimination while state legislation is about access to services (refer to Appendix 1 for definitions from the DDA and Disability Services Act WA).

The World Health Organisation (WHO) gave the first international definitions of disability in 1980 when it published the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (Australian Institute of Health and Welfare, Disability Data briefing, 2002). This definition was reviewed after seven years as it was seen to be too focused on how an individual's functional limitations cause disadvantages and disability (Crow 1996, 57).

The current WHO definition is the International Classification on Functioning, Disability and Health (ICF) which the WHO consider is a bio-psychosocial model of disability that 'synthesises what is true in the medical and social models' (WHO 2002). The ICF measures functioning and health in a matrix which incorporates environmental factors and the ability to participate meaningfully in society. It is seen as an important tool for data and analysis in the paradigm shift from a medical model of disability to a bio-psychosocial model of human functioning (WHO 2002).

Current theories of service provision and support focus on the individual, and focus on community in service development. There is a rise in people with disability and their families wanting direct control over their funding and resources. Direct payments, person centred planning and independent living are considered to be the preferred models of service delivery internationally and are gaining ground in Australia. Person centred planning and direct payments are conceptualised as tools to facilitate individual control and community inclusion. Many of these models focus on the right of people with disabilities to be full citizens and participate in the community. This rights based view is slowly taking precedence over SRV as the underlying force behind disability policy in many areas.

Philosophical and Ideological Trends

When considering the history of disability it can be seen that there has been attitudinal changes over time about the place of people with disability in society. The early years of institutional care were provided from a charitable framework with the expectation that people with disability were a burden and unable to contribute to society. Considerable ideological change has occurred in the past fifty years.

Social Role Valorisation and training

The theory of Normalisation was developed by Neils Bank-Mikkelsen in Denmark and Bengt Nirje in Sweden during the 1960s and 1970s. Bengt Nirje is usually credited with the first definition of normalisation.

The normalisation principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society (Bengt Nirje 1982)

Wolf Wolfensberger saw the potential of the theory and developed it during the 1970s and 1980s and called it Social Role Valorisation (SRV). He suggested that some groups, including people with disabilities, who differ in any way from societal expectations or perceived desirability, are devalued by society and may be poorly treated. His theory suggests that by developing a positive image for devalued groups by building up their competence in roles that society values, for example worker, partner and parent, will overcome devaluing roles and increase rights and opportunities. Wolfensberger suggests that human service providers should build a positive image and help build the skills and competence of their clients. (Wolfensberger 1991).

Although Normalisation and the initial versions of SRV were described as an 'ideology', the most recent formulation explicitly denies that SRV is about what should be done, and reinforces that SRV is intended to be a tool for analysis of the process and effects of Societal Devaluation. Wolfensberger's most recent (1999) definition of SRV is: "the application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for people" (Thomas and Wolfensberger 1999, 125).

SRV is specifically targeted at people with intellectual disability and has been the dominant theory in disability services in the past 40 years. It has had a significant impact on developing legislation, de-institutionalisation, and the emphasis on skill development and training of people with disability.

It has also been criticised particularly from the disability movement. Some of the main criticisms are:

- SRV does not consistently raise consciousness or guarantee there will be concern about socially devalued persons.
- Not all alliances between socially valued and devalued persons are moral, fruitful and advantageous.
- Knowing how social devaluation works in society may still leave one impotent against it.
- SRV advocates a very mainstream, white, middle to upper middle class, Christian bias in terms of the roles people with intellectual disabilities are encouraged to fulfil.
- It is the opposite of an anti-oppression approach and does not consider the struggles and victories of other marginalised groups. It does not build on the rights advanced to others through the civil rights and other movements, and so further alienates people with intellectual disabilities by discouraging alliances with other marginalised groups.
- It individualises disability rather than trying to change the disabling aspects of society.

The most obvious example of SRV in practice is in the citizen advocacy groups where citizens with value are paired with a person with disability to build a relationship over time. The citizen then becomes the advocate and mentor of the person with disability and confers value to the person with disability.

SRV is most often seen as an ideological base in parent-run organisations and service provision organisations.

Medical and Social Models of Disability

It is in the rise of the disability movement and push for deinstitutionalisation, that people with disability have developed theories and models of how disability is perceived and should be treated. The discourse which has occurred in the disability movement has often been separate to that of the service providers and parents groups, and mainly headed by people with physical and sensory disability. The disability movements work on models of disability have at their core a questioning of the values, morals and philosophy which has driven service development for people with disability.

The discussion of models of disability began in England in the 1970s. Currently there is a common understanding of the distinction between the individual model (often called the medical model) and the social model of disability. The key to understanding the difference in these models is in understanding the difference between impairment and disability. The disability movement in the UK has made this distinction quite clearly by stating that a persons impairment (their functional and /or psychosocial/cognitive restriction or loss) was not what made them disabled, but rather the barriers in society - attitudes, access, support or lack of – are disabling (Oliver 1990).

The **medical model of disability** is a model by which illness or disability is the result of a physical condition which is intrinsic to the individual (it is part of that individual's own body), and causes clear disadvantages to the individual. As a result, curing or managing illness or disability revolves around identifying the illness or disability, understanding it and learning to control and alter its course. Often, a medical model of disability is used to justify large investment in 'cures' for disability and genetic screening, as well as technologies and research, when adaptation of the people with disability's environment might ultimately be cheaper and more attainable.

Disability rights groups see the medical model of disability as a civil rights issue, and criticise charitable or medical initiatives that use it in their portrayal of people with disability, because it promotes a negative, disempowered image of people with disabilities, rather than casting disability as a political, social and environmental problem. It focuses the problems on the individual and their impairment and aims to change, treat, cure or prevent the individual from being disabled, and make them as 'normal' as possible (Crow 1996).

The **social model of disability** proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual, or psychological differences, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal' (Oliver 1990). A fundamental aspect of the social model concerns equality. The struggle for equality is often compared to the struggles of other socially marginalised groups. Equal rights are said to give empowerment and the 'ability' to make decisions and the opportunity to live life to the fullest. A related phrase often used by disability rights campaigners, as with other social activism, is "Nothing About Us Without Us" (Crow 1996).

Currently there is debate on whether the social model of disability is actually not encompassing the experience of disability fully enough because people's impairment may still have a great impact on their lives regardless of their disability. The social model could be seen as over externalising the impact of disability on a person's life. Recent books by academics such as Tom Shakespeare (2006) are critiquing the polarisation of social vs medical model of disability and suggesting there needs to be a new research agenda on the complex concept of disability. However this new discourse still has a very strong underlying theme of the responsibility of the community and society in general to accommodate and support people with disability so they do not face exclusion (Crow 1996, 55).

Disability rights, independent living and inclusionist philosophies.

The right to have an independent life as an adult, sometimes using paid support instead of being institutionalised, is a major goal of the disability rights movement, and is the main goal of the similar independent living, inclusion and self-advocacy movements, which are more strongly associated with people with intellectual and psychiatric disabilities. These movements have supported people with disability to live as more active participants in society (Johnson 1983, 82-100). One of the important things about these movements is that the same basic arguments and principles of people with disability having rights and

being given control of their lives are being said by the diverse groups of people with disability.

The basis of these views is that people with disabilities are the experts on their needs. People with disability are encouraged to take the initiative, individually and collectively, in designing and promoting better solutions. A common aim is to replace the specialists concepts of integration, normalisation and rehabilitation with a new paradigm focused on inclusion and individual worth and rights. As well as removing professionals from people's everyday lives, these philosophies promote self-representation and cross-disability inclusion in the disability movement regardless of diagnoses. In the Independent Living philosophy, people with disability are primarily seen as citizens and only secondarily as consumers of healthcare, rehabilitation or support services (Pelka 1997). As citizens in democratic societies people with disability have the same right to participation, to the same range of options, degree of freedom, control and self-determination in every day life that other citizens take for granted.

Rights based activists demand the removal of infrastructural, institutional and attitudinal barriers. The principle of universal design is seen as basis for structural change and inclusion. Depending on the individual's disability, support services such as assistive technology, income supplements or personal assistance are seen as necessary to achieve equal opportunities. From this perspective the service system should be designed to enable people with disability to control their services, to freely choose among competing service providers and to live with dignity in the community. Cash benefits or direct payments are seen as ideal systems by Independent Living activists over services in kind, to get outcomes which enhance quality of life and have cost-efficiency (Pelka 1997).

These ideas are similar to the social model of disability but have a much stronger underlying theme of shifting power and control to people with disability. They are also more pragmatic in leading to specific tools such as person centred planning and direct payments to achieve these goals. In Australia and the UK there are groups using this as the basis for what they are calling Supported Living in acknowledgement of the support needed to live and take control of ones own life with an intellectual disability.

Current Models and approaches

There has been a policy shift in Australia towards individualised or person-centred approaches. All states now have funding individually allocated although this does not mean that the supports received are person centred or self-determined by people with disability. In NSW, Victoria and WA there are pilots or programs in place where people with disability and their families receive their funding allocation as a direct payment. At this stage these programs all have differing levels of who can receive funding this way and the accountability required.

There are also many different services and programs both in Australia and overseas, which are still working in institutional and medical models, or are somewhere in between. There seems to be recognition of the need to give people with disability a level of control over their lives and services but also a concern for the level of risk and need for safeguards which can often swing the balance back to inflexible and restrictive practices. Sometimes the degree to which the services or systems have changed is dependant on the

perspective of who is making that analysis.

In all states of Australia there are service providers and family run/consumer run organisations that use the tools of person centred planning, microboards, keyring models, and circles of support because they believe it is the best way to have individualised support which can lead to community inclusion.

Many terms are used which often overlap or seem similar but have been developed in different places such as independent living and supported living, self-determination or self-management and individualised budgets. To assist in identifying similarities and differences the key elements of a range of models have been identified.

Detailed below are examples of services which are current and are using elements of inclusion and self-determination, as well as examples of current services which are more traditional. See appendix 2 for more examples and links to websites. They have been grouped under:

- Community engagement
- Accommodation and day activity
- Independent Living

Models of community engagement

Community inclusion is not about people with disability doing activities in a community setting or living in a house in the suburbs. When community inclusion is envisioned it is about people with disability 'being of the community' which means:

- People know you, you may be a regular at the local supermarket or coffee shop.
- You feel safe and that you are in familiar surroundings.
- You have reciprocal relationships with others.
- There is a sense of belonging.
- You are valued and have a sense of self-worth.
- You have social connections and networks in the community.
- You are asked to participate and work together with others in the community.
- Your views are listened to.

(De Hoedt 2002)

Elements of community inclusion

Community inclusion is seen as part of the paradigm shift in the disability sector, and the practice of community inclusion has the following key elements:

- Relationship building and relationship development skills are facilitated.
- Awareness of disability and community education, particularly to generic services and businesses.
- Focus on people with disabilities as individuals with lifestyle choices, interests and desires.
- People with disability have life goals they set, change and aspire to with support from formal and informal networks in the community.
- People with disability actively participating in their lives, eg shopping, cooking, cleaning, paying bills etc.
- People with disability supported (if needed) to actively participate in their community eg vote, take part in council reference groups or other local groups such

as dog walking etc.
(De Hoedt 2002)(Kennedy, Sanderson and Wilson 2002)

In Australia we have federal government policies to promote mainstreaming in education, access to services and to promote open employment through the Disability Discrimination Act (DDA) and the related standards. Disability action plans are used by organisations at all levels (private sector and public sector) to show that people with disability are accounted for in organisations policies and practice (HREOC, Disability Rights website). The criticism of these is that they are not enforced as it is a complaints-based mechanism for checking compliance to the DDA. The UK and USA each have equivalent legislation however in the USA the American with Disabilities Act is further enhanced by the Bill of Rights. In the UK the Disability Rights Commission enforces their DDA and can take legal action for non-compliance under their Disability Equality Duty.

At a state level most states require government agencies and local government to provide some type of disability action or access plan. In South Australia there is a traffic light tool which measures agencies compliance, and in WA there is reporting of the implementation of Disability Inclusion and Action Plans, to the Disability Services Commission.

Currently (Oct 2008) the new Australian Government is developing a Social Inclusion Agenda which will incorporate a National Disability Strategy and National Mental Health and Disability Employment Strategy and it is yet to see how these will work in practice. Disability advocates hope that this approach will be rights based and use the social model of disability to address systemic change. New Zealand has gone through a similar process and is seen as a leader in this area of disability rights.

Community development and education is seen as a key role in promoting social inclusion. There are many examples of specific programs and initiatives which do this. Successful projects include:

- Bar None – a project in Victoria which involved training community newspaper journalists in how to portray people with disability and disability issues, while giving them stories from people with disability nominated for doing things in their local communities.
- Count Us In – Western Australia's broad community education campaign and information for community.
- "Talk" Disability Rights Commission UK and others – In the UK from 2006 the Disability Rights Commission did a series of advertisements that are on Youtube turning the experience of people with disability in employment on its head. The newer Equal Opportunity and Human Rights Commission in the UK has followed up with a series on their website called Equally Different were a range of well known and ordinary people from different backgrounds (CaLD, disabled, war veteran) tell why they are different.
- Creature Discomforts – Leonard Cheshire Disability Rights in the UK have a series of commercials done by the well known Aardman Animations studio, which uses the stories of real people with disability with animated animals.

More long-term community development work is also done by the Local Area Coordinators in WA, where they build connections over time with the area they work in. A similar approach is in Victoria although the workers are located in local government and do not do any individual or disability services work, but only focus on community mapping, and community projects and connections which include people with disability in mainstream activities. These are called the Metro Access and Rural Access workers.

Models of accommodation and day activity support

There are many different models of accommodation for people with disability, most now in the community with different arrangements of housing and support. However the move to de-institutionalisation has meant there is a great fear of institutionalisation of accommodation and day support facilities. The term institution has become a word heavily weighted with the concepts of isolation, segregation, abuse and neglect. In fact it is a particular set of institutional features which the disability sector is trying to move away from in de-institutionalisation.

Elements of an institution

- There are rules and guidelines for people with disabilities which are set and enforced by others.
- The program, residence or service has a structure which is imposed by others, such as set times for activities/meals.
- A hierarchical system of management is in place.
- There are limited or no choices and options available.
- People with disability are in settings which are segregated from others in the community, such as purpose built activity centres or disability specific recreation groups.
- There are predominately group activities.
- It is considered a sheltered, 'safe' environment, with many limits to 'risk' in place.
- There is a high staff-to-client ratio, with limited individual interaction or relationship building.
- There are expectations of behaviour which are embedded in the culture of the institution.

(De Hoedt 2002) (Crow 1996)

There are still large residential homes in Australia and in WA. Some are considered C class hospitals or hostels but they are still providing permanent homes for people with disability. Some are more modern with small units or rooms with en suites, while some still have large shared bathrooms. Some have from 10 to 30 residents others up to 100 people. There are also still many people with disability under 50 years of age living in aged care facilities because of high medical support needs. Examples of large residential facilities in WA include the Quadriplegic Centre, Brightwater Endeavour House, and Kenwick Mews. This type of accommodation holds a much higher risk of residents becoming institutionalised.

There are a lot more models of accommodation support that fit somewhere in between what is considered institutional and what is individualised and flexible. There are many programs which provide support for people with disability to remain living in their own or their family home. The federally funded Home and Community Care (HACC) program

provides very small amounts of support usually through local councils. Also many state governments provide in-home respite, and specific attendant care programs which are usually restricted in hours available, and even when funding mechanisms are flexible have restrictions on use eg only to be used for support staff. However, they do provide an opportunity for people who need support to stay living in their own homes or in private or public rental.

Where government or non-government organisations are providing housing and support there are shared housing options. These come under a number of names such as group homes, shared supported accommodation and community residential units. Typically they are houses in the community of four to six individuals often with similar disabilities and support needs and with staff coming in to support all residents. These homes can provide quite individualised support and can assist people to be more connected to their local community.

Active Support is a method of encouraging residents in group homes to do as much as they are able to in their own homes and community with person centred plans to assist in identifying abilities, skills, likes and support needed. Research in Victoria on power sharing and active participation in group homes has led to this strategy being used extensively in state run facilities as well as being picked up by non-government accommodation providers (DHS 2002a). It is these types of residential facility that could and sometimes have, started to increase in size to take 10 residents or more.

Cluster housing is the other main model used where people have high support needs and economies of scale still play a factor in costs. People with disability have their own units or houses close together with staff in an office in one unit or something similar. Sometimes these can be quite large like a retirement village, but there are also quite innovative versions where houses or units are within a 2km radius for ease of sharing support staff without being a segregated block of disability housing. Some co-operative models of housing support have also got co-operatives for personal support where they are close geographically. Some cluster housing is segregated into disability types because they are owned by disability specific groups such as the MS society. A recent report by the Centre for Developmental Disability Studies for the Victorian Department of Human Services (DHS 2008) says "Existing evidence indicates poorer outcomes for people with a disability living in cluster housing as against dispersed housing."

A small percentage of people with disability live in innovative situations such as lead tenancy arrangements or free rent for support type arrangements. L'arche is a community group that are very well established in Europe and has started some communities in Australia that use this type of arrangement. They are about developing a community where people with disability are supported to live in a share house with community members.

There are a range of options available for people with disability who need daytime support or want to do meaningful activities in their lives. There are also many people with disabilities who require support in the day but do not want to be involved in these options and cannot get the personal care support to work or be involved in other activities. There are also many people with disability who are supported to participate in open employment.

Traditionally many people with disability have gone to day centres for their day support, particularly people with intellectual and multiple disability, and those with physical impairments such as cerebral palsy and muscular dystrophy. This is where a person goes to a place and participates in group or individual activities with staff support. Often there are a range of activities available and some services do group outings or have individual programs where someone is supported to access the community. A great example of a service which started out as a traditional day placement centre but now has a wide range of individualised options and services, including encouraging and helping people to find work at any level is Jay Nolan Community Services in California. It uses person centred planning to support people to meet their goals. The trend in this area is for more services to be individualised and access the community. In Australia, Melba Support Services in Victoria provides individualised programs. This is an area which is picking up on using person centred planning to assist in their individualised services.

For those people who want to work but need support or have difficulty meeting productivity levels there are business services, formerly called sheltered workshops, and supported employment options. There has been criticism of how much people are paid in business services and also whether they provide a meaningful activity for someone. In some cases business services are used as a transition from sheltered employment to a supported employment option in the community. Disability Employment Network providers support people to find supported employment and open employment. These are federally funded programs.

Models of independent and supported living

The key elements of independent and supported living is that control is with people with disability and their families, planning for support is whole of life and person centred, and there is transparency and flexibility in funding. This approach is not a model and in fact does not agree with a model driven system but rather systems that are transparent, flexible and working to meet the diverse and individual needs of people with disability. Often this about giving people with disability self-determination. Activists which are lobbying for people with disability to have more control over their lives have tried to identify the key elements need for the change to independent living models.

Elements of self-determination (self-managed care, individual control, supported living)

- Freedom, for people with disability to have control and use of their funds to build a life rather than have purchased for them a pre-determined program, with freedom of choice in how they use their funds.
- Authority, so people with disability really do carry meaningful control over their life and are respected as having that control.
- Support, from both formal and informal support networks which enable participation in the life of the persons community.
- Responsibility, where people living with disability are expected to assume responsibility for not being passive recipients of support but for also contributing something to their communities, like any other citizen.
- The expert is the person with disability and their family.
- Separating the provision of housing and support to give people flexibility to change and move.

- Key emphasis is on relationship building.
(Kinsella 2001) (Williams 2007)

Some of the examples of models or approaches which are currently popular and fall under the philosophy of independent living are more like tools which can be used to achieve community inclusion and self-determination. Sometimes these tools when used in isolation or without the culture of the underlying philosophies and principles of inclusion and self-determination, can become as disempowering and inflexible as other institutional methods (Williams 2007). Traditional case management or case-based approaches can be empowering and flexible in the right systems but can also be as equally dis-empowering when used to control and limit people's choices.

Elements of traditional case management

A case management role is often used to assist people with disabilities in accessing services and support. The following elements are those aspects of traditional case management which may serve to continue institutional practices and systems and in doing so limit and de-value people with disability and their families. Many case managers and professionals in similar roles would see themselves as facilitators or brokers yet still retain some of these elements in their work.

- The role is time limited such as a three-month period or time limited such as 1 hour a fortnight to meet competing demands from new referrals and other clients.
- The role involves assessment of eligibility for services and acts as a 'gatekeeper' for the service system and resources available.
- The majority of referrals or placements for support are to existing and disability-specific services and providers
- Options for people with disability and their families are censored and narrowed down by the case manager

(Williams 2007)

Person-centred planning is one of the main tools used for creating independent living. It is a process of life planning for individuals, based around the principles of inclusion and the social model of disability. In person-centred planning the process, as well as the product, is owned and controlled by the person (and sometimes their closest family and friends) (Circles Network 2008). Person-centred planning involves the development of a "toolbox" of methods and resources that enable people with disability to choose their own pathways to success. Planners or facilitators help them to figure out where they want to go and how best to get there (Cornell University Person Centred Planning Education Site 2008).

Elements of person-centred planning

- The person is at the centre
- The person is consulted throughout the planning process
- The person chooses who to involve in the process
- The person chooses the setting and timing of meetings
- Family members and friends are partners in planning
- The plan reflects what's important to the person, their capacities and the support they require
- There is a shared understanding that the person is the expert
- The plan results in actions that are about life, not just services, and reflects what is

possible, not just what is available

- The plan results in ongoing listening learning and further action

(Sanderson 2000)

There are many tools of person centred planning which are used, the most notable being Essential Lifestyle Planning, Personal Futures Planning, MAPS and PATH. An element in all of these is the expectation that a planner will assist in putting the plan together. The elements of planning and facilitation are:

- A commitment to know and seek to understand
- A conscious resolve to be of genuine service
- An openness to being guided by the person
- A willingness to struggle for difficult goals
- Flexibility, creativity, and openness to trying what might be possible
- A willingness to enhance the humanity and dignity of the person
- To look for the good in people and help to bring it out
- To have done planning for yourself to understand the process

(Cornell University Person Centred Planning Education Site 2008)

In person centred planning there is an assumption that the planner will assist the person with disability to look outside their comfort zone and bring options and information to the planning process that is outside of the traditional disability support services. It is a tool for inclusion and supported living mostly used with people with intellectual disabilities.

Following are examples of organisations, projects and systems which use person centred planning as a key tool in their approach to independent living:

- One By One - One By One is a Victorian family-governed initiative, founded in 2001, which supports up to 10 people. Each person, with their support network, develops their own vision of what they want in a person centred plan. One by One uses a part-time coordinator. A host agency performs administrative and legal functions, but authority over steering and creating support arrangements remains with the people themselves and their families.
- PLAN Canada - PLAN is a not-for-profit charity created by and for families who have a relative with a disability. The organisation assists families to develop a personal future plan for themselves and the family member with a disability. It helps establish a caring personal network, provide advice and referral on alternatives to the current government administered social services, monitor the quality of programs and services a person receives and provide recommendations and advice on home ownership and alternatives to legal guardianship.
- Victorian Individualised Planning and Support – In Victoria all programs with individually allocated funding have been rolled together in a new approach where people are assessed for funding, develop their person centred plan and are then able to choose a range of ways their funding can be administered to purchase services. This has amalgamated previous separate programs such as in-home support, respite, community access funding and post school options/ alternatives to employment. People with disability are able to do whole of life planning and are supported by facilitators to explore options outside of disability specific services.

Individualised funding is the other key tool which is used with person centred planning to give control to people with disability. The term individualised funding usually refers to a range of ways that the person with disability can know how much funding they will get and control what it is used to purchase.

Elements of individualised funding

- The person knows how much funding they will get
- The person has genuine control of the funding
- The person has a plan which they have developed
- The person receives support to comply with accountability

(Williams 2007)

The Direct Payments program in the UK with the In Control method of support and control is a great example of individualised funding. In Control is a group started by parents in the UK who wanted their sons and daughters to have more control over their lives and the funding they received. In particular they have developed a framework for individualised budgets which means all people with disabilities can have individualised funding, self-directed support and ultimately independent living. They have worked in partnership with a number of councils in the UK and implemented the framework successfully with people with disability. The things which make it work are the support from Centres for Independent Living and the very small number of rules that are set to limit peoples purchasing. The accountability is simple and once a year and comes back to the persons plan that they have developed. This is a shift in power which puts responsibility and accountability back to the person with a disability, as well as choice and control. (Kinsella 2000)

In Victoria there has been a project using similar principles called the Direct Payments Project. This is a project which trialled 10 people with disability and /or family receiving their funding in monthly payments, with minor restriction on what could be purchased but assisting people to develop a person centred plan to guide their spending. The project was extremely successful for participants in terms of flexibility, control and choice and it is now being expanded to 100 people.

Individualised funding does not necessarily mean the money goes directly to the person or family to purchase supports. However it does have to be controlled by the person and/or their family in terms of the decisions on what to purchase to meet their needs. The most common methods of individualised funding are:

- funding goes direct to a service provider of the persons choice and is portable so the person can change service provider at any time;
- funding goes to a financial intermediary who pays the bills for whatever the person purchases;
- funding goes to a broker/microboard/circle of support who work with the person to purchase services and support; and
- funding goes direct to the individual or a guardian to purchase the support and services they need.

(Williams 2007)

Some examples of organisations which have specialised in these key supports such as microboards and circles of support are:

- KeyRing Living Support Networks - People supported by KeyRing live in ordinary homes within walking distance of each other in a community. A community living worker who is similar to a case manager or broker, builds supports around each individual in this community.
- Vela Microboards -A Vela Microboard is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people address the person's planning and support needs in an empowering and customised fashion. A Vela Microboard comes out of the person centred planning philosophy and is created for the sole support of one individual. The process must be focused on the dreams and wishes of the person for whom the board is being created. All Microboard members must be in a close, voluntary, and committed relationship with the person for whom the board is being created. These close relationships are the foundation of the board and must be honoured above all other activities.
- Circles Network - Circles Network is a UK voluntary organisation based around the key principles of inclusion and person centred planning approaches. Circles Network provides individualised personal support using the tools of person centred planning to facilitate inclusion in the community, principally through the setting up of Circles of Support and through individual projects for specific areas of need.

In WA the Local Area Co-ordinator (LAC) role was developed to provide individual support, information, and community development. It is seen as being a relatively successful program, but may not meet all the elements to provide a framework for independent living. There is still an emphasis on rules about what can be purchased and how funding can be used rather than providing support mechanisms to explore more options and provide education. This is often an issue of resources.

In the UK and elsewhere it has been shown that people with disability and their families are usually more cost effective in their purchasing when they are in control, yet other resources need to be developed to support and educate people with disability and their families in the role of purchaser (Williams 2007). This means at best it would cost governments less and at worse it would cost the same. In WA there are also still numerous funding streams for specific purposes which fragment and constrain support for people with disability, with other services that can't be purchased that are separately run such as therapies and continence assistance.

The trend internationally and nationally is towards models which are 'whole of life' and the underpinning philosophy is one of self-determination, independent living, supported living, citizenship and rights based. More states are using the tools of individualised funding and allowing more consumer control of services. The paradigm shift we are moving to is one which takes the philosophies of the social model of disability and an independent living and rights based approach.

Call for Change

People with disability through advocacy organisations and peak bodies are calling for community inclusion to work as an agent of change for people with disability. Suggestions that have come from the disability sector through forums and reports suggest a multi-level approach is needed, working with different stakeholders at individual, community and societal levels.

The common themes which have come from consultations with people with disability reflect the elements of community inclusion and self-determination detailed already. People with disability want their voice to be heard. They want to have control of their own lives and be involved in the development of policy and services which are meant to assist them. People with disability are not always confident and are themselves part of a culture which has not given them opportunities to speak up. Training and skill development of people with disability as well as support workers is needed to help establish these goals as real change. There are also strong calls for better education and awareness raising of disability in the wider community that is not a charity message. (DHS 2002b) (AFDO Creative Solutions Report 2007) (De Hoedt 2002)

Disability advocates suggest that the disability professionals have to let go and give the lead to people with a disability. Interestingly, in traditional community development, there is an assumption that the community worker is not the expert (Kenny 1994). One advocate has stated that "The disability sector has a lot of charitable and paternalistic baggage to shake off." (AFDO Creative Solutions Report 2007).

Issues impacting on current and future approaches

Segregation and Isolation

The closing down of institutions does not mean there has been an end to isolation and segregation of people with a disability. Group homes have become the replacement of large institutions for accommodation of people with a disability, with the supposed advantage of being ordinary homes where people live in the community. However, the Senate Report in 2005, *Protecting vulnerable children: A national challenge* (2005) showed otherwise:

...despite being in the community, group homes do not mean greater participation in community activities, better quality care or necessarily that individuals have their needs met or are protected from abuse and neglect; an incompatibility of residents often leads to injury, aggression, hostility, threats, intimidation and fear... (section 5.57).

Moreover, as the following statement from a parent in the Senate Report (2005) shows, isolation can also occur in the family home.

This parent advised that: Because of the almost non-existent support to families of children with difficult behaviour or disabilities...the 'inclusionist' ideology has led to many families becoming institutionalised. It has increased the

new 'mini-institution', the family home. Of great concern is that these 'mini-institutions', these families, are invisible to the policy-makers and ideologues. Their isolation and loneliness is not factored into policy because they neither have the time nor the energy to agitate and be heard... (section 5.59).

Other literature on people with intellectual disability living in the community, be it in group homes or other alternatives, concurs with these statements from the Senate Report. The initial report on Power Sharing and Direct Care Staff Interaction with Residents of Disability Accommodation Services, by the Victorian Government Department of Human Services (DHS 2002a, 24), states in its literature review that putting people with intellectual disability in the community does not automatically mean there will be participation and self-determination. This report shows a correlation between the behaviour of staff to residents, and the self-determination and confidence of residents. Staff can isolate residents with their behaviour and the expectation of the staff role being one merely of physical support (DHS 2002a).

Many believe that the isolation and segregation still occurring is because of lack of system change and support tools to support inclusion and de-institutionalisation (Kinsella 2001). Moves to more individualised approaches carry a high risk of further isolating people with disability if there is no support for inclusion.

Organisational culture

One of the pitfalls discussed in the disability movement to be aware of in using these tools which focus on the individual or family being in control, is that if the system and culture do not change then it can become just another program with the same inflexible systems. In the UK the 'In Control' system of direct payments works because there are very few rules about what people can do with their funding and an expectation by the system that people with disabilities and their families know what they need. This has led to a rise in Centres for independent Living which provide support and guidance and are run by people with disability. There has also been an increase in the variety of support agencies and use of mainstream community supports. (Kinsella 2001). If the service providers currently available are not reflecting and reacting to the changes occurring then the service system can become stale. The other impact of the service system not changing is that it does not make space for new services and organisations, which is essential for maintaining a healthy, vibrant and creative sector.

Changing more than language. Well-known disability academics and thinkers such as Michael Kendrick and John O'Brien make similar points. John O'Brien states "It is so easy to change our language without changing our structure or our culture" (Person Centred Planning Education Site 2008). This is alluding to the propensity of many organisations including government to use the new label for what they are doing, run some training and then fall back into the same systems. Michael Kendrick (2000) brings this issue to a personal level by stating that the core beliefs held by professionals, policy makers, and support workers will define how they work. So change and reflection on the system and culture we work in must happen at every level, and we must act and work and relate to people with disability in a true belief of person centredness as our value base (Kendrick

2000).

The hold of specialist services in the sector. An example of how ingrained culture can be a roadblock to change is the contradiction that exists when, as a sector, we promote community inclusion, while handing out advice and resources to attend specialist and segregated activities. There continue to be significant numbers of groups around which provide activities for people with special needs, as well as special schools and other special programs. It isn't so much that these exist as the fact that doctors, case managers and therapists advise people and families that they need specialist support and the best place to get that support is in a specialist program (Nelson, Zoellick and Dillon 2000). Unfortunately this is not helped by limited support and resources to remove environmental barriers, and increase education and support in the mainstream services.

The need to bring everyone along with the change. The disability sector is at different points in the change process so organisational culture and systemic barriers to change such as those mentioned above will impact on which direction change may take. Some groups such as medical professionals have not been engaged in the discourse on the changing system for people with disability and so are still perpetuating a culture which is not necessarily wanted by people with disability and their families.

Workforce and demographic issues

Lack of Support Staff. One of the biggest issues in the disability services sector is lack of support staff. This is two fold in that there is currently a crisis in available skilled and unskilled support staff, and more often parents or partners are unable to take on a caring role due to work and money constraints and so are reliant on paid support. In WA there are also suburbs and regional areas where this is worse than others. Unfortunately the economic boom is taking workers away from jobs in the health and social welfare sectors. It is unlikely this will change significantly without an influx of people willing to do this work or major changes to pay rates and career structures for workers in the sector. The impact of this is already apparent when there is discussion at federal and state levels of ten bed accommodation facilities and cluster housing which is more reminiscent of retirement villages as an answer to lack of staff and funding resources.

A flexible workforce? Service providers, family groups and people with disability have started engaging and employing support workers in different ways to try to overcome workforce issues as well as provide more flexible and individualised services. Examples are support workers as contractors with their own ABNs, agencies acting as payroll service only, and people paying cash in hand. Some of the issues which may impact future service systems are:

- Taxation rules on the definition of a contractor
- Workers not covered by workers compensation insurance
- Adequate and appropriate training not always occurring
- Real costs of support staff not identified

The diverse work of disability support workers. The work that support staff do is often seen as being homogeneous and paid at fairly standard rates while in reality there can be quite different roles required dependant on the person with disability. Some work is about prompting someone to do things for themselves, other work is personal bordering on

medical care, some is purely domestic, some is about helping someone access the community. These can be with different ages and disability types yet there are standard training courses for disability support workers which may not take all these aspects into account. For example assisting someone to access the community may involve skills in helping them to build a relationship outside of paid workers. Whereas assisting someone else to get out of bed or prepare a meal may involve the skill of manual handling. Some people with disability do not want staff who have taken training courses as it stops them being flexible in responding to individual needs.

Increase in age related disabilities. Our changing demographic profile also means that more staff will be required in the future for an ageing population that will increase the number of people with age related disability. The other impact of our ageing population is the ageing carers of adults with disabilities who have had very little or no support in the past. This has sometimes been because the service system has prioritised those most in need, and as these people have carers they have not been on the top of waiting lists. Sometimes it has been because the carers have not wanted support from government. The result is that there will be an impact on the guardianship, service systems, and accommodation services in the near future.

Fragmentation

In the disability sector both funding and service provision has traditionally been very silo based. When there was an approach that had block funding, those funds went to specific groups to do specific activities. This led to inflexible systems and people with disability were stuck using the services that were available while the barriers to their participation lay elsewhere. With individualised funding money is attached to the person but the policy and practice in Australia is still of discrete funding buckets with specific eligibility criteria eg day centre options, accommodation options, community access.

The CSTDA categories of funding and split funding between commonwealth and state maintains a fractured system. WA started to use the Combined Application Process for funding as one way of addressing this yet it still fragments a persons life into sections with specific outcomes tied to certain funds. Also any services from HACC, Commonwealth Carer Respite, and Employment services are all federal responsibility. Victoria has worked on an initiative which uses the Commonwealth Carer Respite Service as a gateway for referral and funding to all respite services and funding both state and federal to reduce the double up of service.

Both service providers and people with disability are calling for more flexible and streamlined approaches for funding and accountability. Yet many service providers and people with disability are also saying they need some specialist support to have understanding of unique needs such as people with disability from culturally and linguistically diverse backgrounds. How specialist support is provided in a main streamed and single point referral system will impact on service system design.

Who gets services

This is always an area of contention because resource allocation is an issue. The question of who gets services has a number of elements which impact on how the question is

answered and will impact on future approaches.

Whose voice is being heard by the resource allocators? Currently the voice of carers is very strong. There is a lot of media coverage on carers and carer issues. This has been picked up by government with initiatives such as the carers bonus and increases to respite programs. This is a legitimate area of need, however the group of people with disabilities who need support and face barriers to participation is much bigger than just the group with carers yet their voice is not so strong. There are also new voices in the disability sector (HIV/AIDS).

At a program level it is often stated by workers that those who prove they are suffering and disadvantaged the most will receive services. Often this is because of limited resources and restrictions on eligibility criteria or program numbers.

How services and definitions are framed can have an impact on who gets service.

The classic example is that disability services are for those aged under 65. Currently many people with disability access age related services to top up their support (such as from HACC and things like meals-on-wheels). In the future those aged over 65 with disability may be tapping in to disability services for their support. Also disability doesn't stop at 65 and with life expectancy increasing, people with disability who are ageing will be trying to access two systems.

In many states, including WA, mental illness or psychiatric disability is still separate, in practice if not in the written definition. It has been difficult to separate the supports for acute and chronic needs in episodic illness. This has often lead to people with multiple disabilities which include a psychiatric disability getting no support for that need, or no support for their other disability. There are also new health areas falling under disability such as HIV/AIDS, Autism Spectrum Disorder and Asperger's Syndrome, and people with allergies and chemical trauma.

How this changing face of disability fits into the definitions that policy makers use will impact on who receives support and services and what form that support takes. The WHO biopsychosocial model is used by the Australian Institute of Health and Welfare but there is little evidence it is used elsewhere. It is a model which defines disability in ways which include environmental factors and the impact of impairment on participation, whereas the definitions in legislation aim to prescribe disability to an impairment.

Multiple Services systems. In Australia a person with disability could have a compensation payout and purchase private services for a high hourly rate, while people reliant on state funding can get services at a different rate with restrictions on how much. Then there are federally funded services such as Home and Community Care and Department of Veteran Affairs who pay another hourly rate with different restrictions on funds. Most programs also have restriction on access to people already receiving services elsewhere. Those with high needs can often access multiple services but must provide multiple applications and accountability. WA has the Combined Application Process which assists with state funded services.

These multiple systems often require service providers to have multiple accounting

systems dependent on who is paying and what rate is being charged. There are also incidences of people with disability who are born with their disability stating that they wish they had acquired their disability through an accident to get compensation so they could afford more support. While those with compensation payouts wonder why they pay higher rates for all services.

Where you live. For those who live in remote and rural areas there is often little choice or options for what service you might get, if you can even get services. Family and informal support networks can be much stronger in smaller communities, but still may not meet the needs of the person with disability or the respite needs of carers.

Challenging behaviour and high support needs. There are groups within the broad group of people with disability who often are quite limited in the services they get because they are seen as being too high maintenance or challenging. Many of the websites on person centred planning and direct payments give examples of people whose behaviour changed when they had more control over their lives, or when the planning process highlighted their abilities and focused support on enabling those abilities. Further research and data gathering in this area is needed to know that a changing service system can bring this group along and not have a sub-class of people who remain further disadvantaged.

UN convention on the rights of persons with disabilities

Australia has signed and ratified the UN convention on the rights of persons with disabilities. By signing and ratifying the Convention, nations agree to work to achieve these rights as and when they can. This recognises that while countries may be at different stages of progress towards achieving full rights, all countries can improve and all should be working towards ending discrimination.

Participation of people with disability. One of the most important things about the development of this convention is that it has involved the highest level of participation by representatives of civil society of any human rights convention, or indeed any other United Nations process, in history. This participation was overwhelmingly that of people with disability and their representative organisations. People with disability are also expected and encouraged through the convention text to be participating in the implementation and monitoring of the convention.

Civil, political, economic social and cultural rights. The Convention requires countries to provide for the full inclusion of people with disability in the community and to create conditions that enable people to live independently should they choose. These are all encompassing requirements and the convention goes well beyond civil and political rights. (HREOC 2007)

The convention encompasses so many aspects of our daily lives its impact may be seen in the way it brings disability rights to more aspects of the community than currently. It could be the tool which meshes human rights legislation to the reality of policy and program development across government.

For the disability advocacy sector it provides a tool for monitoring that is rights based and gives a legal framework for lobbying and advocacy on human rights, rather than relying on

the need to prove discrimination.

Resources

Unmet need through lack of resources always seems to be an issue in the disability sector. Disability is not always seen as a priority area when government is making budget decisions. In the future resources may very likely be moving to support the aging population.

Dedicated funding for disability? There is discussion currently on the setting up of a dedicated funding stream for the disability services sector. It is being discussed as a National Disability Insurance Scheme with the 'insurance' being a compulsory levy similar to the Medicare levy or the third party insurance paid on drivers' licences. This is something which has been on the agenda for different groups over many years, most recently being lobbied for as a 'Catastrophic Injury Insurance' by the Young People in Nursing Homes Alliance.

Priority of resource use. The other issue of resource use which impacts on future service delivery is what it is used for. Will resources go in to making accessible environments which may reduce the need for staff intensive supports? The immediate need for support now usually means that broader infrastructure costs are not accounted for or are sought elsewhere, such as other government departments for whom disability access is not a priority.

Technology is a resource which is often talked about in the disability sector but often underutilised because of cost. Again the uptake and improvement in technology could mean reduced reliance on support staff but may cost a lot more for it to be available to all those who need it.

Political and Social Environment

Federal system. Currently (as at September 2008) at both the federal and state levels we have Labor governments. This is already showing better co-operation and communication for negotiation of the CSTDA. The current Federal Government is renegotiating the CSTDA and has successfully made agreement with the states on a number of issues including funding for unmet need, yet the previous Federal Government was prepared to move to direct funding of services for people with disability that were normally state responsibilities such as accommodation when its negotiations failed. This led to discussion and debate in the disability sector about the purpose of the CSTDA and what was good or bad about it. This debate may continue as there are many discussions which have come from things like the 2020 Summit about using a National Disability Insurance Scheme to have a dedicated source of funding for disability support, and having 'one stop shops' for disability. These solutions, many which have come from overseas systems such as the UK where there are two main tiers of government instead of three, raises questions on who is responsible and how funding is allocated. It is also likely that this debate will continue again when the CSTDA next comes up for negotiation in five years time.

The power to influence decision making. It is not necessarily people with disability who are influencing decisions about disability policy. A prime example of this is the Access to

Premises standard of the DDA which did not move forward with the last Federal Government because of strong lobby from the building industry. With the new government it is moving closer to being accepted. The disability sector in WA may find change will occur with a state election due soon (as at September 2008). Part of the change of a new government is not necessarily the political party in power but the fact that it is new and may wish to make a mark and show it is listening to constituents in the first year of office.

Efficient use of government funding. The area of disability is one which any government will find hard to reduce spending in, however governments may see individualised funding and direct payments as a way of cutting costs if they do not provide the supports and community development that is espoused by the disability movement in this approach to services.

Prosperous times encourage community thinking. The federal government has also instigated initiatives such as the Social Inclusion Board which is also happening at state levels. This need to express the rhetoric of inclusion is a result of the current social environment yet an economic downturn may change this context. Apart from the increased emphasis on inclusion there is also an increased emphasis on rights. Both Victoria and the ACT have their own Charter of Rights in legislation and there is a strong lobby for their to be a federal Charter of Rights. However it is also important to note here that there has been and continues to be an emphasis on privatisation and deregulation in all sectors including the community sector, which is at odds with the rhetoric of community and inclusion.

Possible Future trends

From the information given above and the current social and political environment a number of possible future trends in service models and approaches can be suggested:

- Whole of government approaches – following through with the emphasis on social inclusion and rights it is possible to see a greater cross-government approach to disability policy and reporting than there is currently. Government departments related to planning, infrastructure, transport, housing, education and health are all needing to do more in relation to disability as the DDA Standards are beginning to have an impact. The UN Convention on the Rights of Persons with Disability and any possible Charter of Rights will mean more cross government accountability to people with disability also.
- Community development at a local level – the impact of climate change and globalisation may improve the development of local economic systems such as co-ops and relationship building through sharing of resources at a local level.
- One stop shop or single point referral system – this could certainly happen at federal or state levels. The National Disability Strategy being developed by the federal government may see this model for all employment related supports. It is already happening for some areas such as respite in Victoria and people with disability are asking for a simpler and more accessible service system. This would not necessarily mean the end of specialist support or advocacy services as there is also a strong lobby for their expertise to remain. Individualised approaches can fit into this model if the rules and procedures are simple and allow lots of flexibility.

- Whole of life planning – Person centred planning and planning which encompasses more than a persons support needs is being used more and more in the disability sector. The issues for this being used more widely in the future is the fragmentation of the system. Funding buckets are becoming more amalgamated or at least they are behind the scenes in the application process but there is still a distinction between key areas like home support and education or employment support. We could see situations where a person has a lifestyle plan with every service they use. More likely there would be one plan which incorporates all aspects of a persons lifestyle and supports that has actions shared by different groups.
- Brokers/facilitators in key role – The role of the case manager in the disability sector may be replaced by planners, brokers and facilitators who assist people with disability and their families to develop person centred plans, and research purchasing options. They have an accountability totally to the person they are working for as that is who may pay them and they build a long term relationship with.
- Direct funding for all supports and individual budgets – Disability services are already well on the way to becoming totally individualised in its funding. The amount of control and choice people with disability and their families have over their funding will increase with a strong likelihood of direct payments or some form of financial intermediary being available for all people with disability across all service types. The issue is that this may not be balanced by increasing access to local community and mainstream services.
- National or State Disability Insurance – There is an increasing need for disability services to have a dedicated source of funding which matches the numbers of people living with disability and can be used for environment and infrastructure development. This could start as no-fault catastrophic injury insurance, or could be broadened to become an aged and disability support dedicated funding stream. Dedicated funding could increase the use of technology and aids and equipment, and provide for better wages and career choices for incentives to be support workers.
- Larger group homes and cluster arrangements – There is a high possibility that the lack of paid support staff and ageing population will lead to group homes of 8-10 people and larger cluster arrangements than are currently available.
- Disability-specific day centres becoming community centres to pool resources – With a rise in programs and projects to increase community inclusion and community access to mainstream services for people with disability, it may be possible that specialist disability activity centres open their doors to provide mainstream and integrated recreational activities and services.
- Increase in family/person with disability controlled co-ops/independent living support groups - As systems have already changed in WA to being more individualised and flexible there has been a rise in small family governed groups. It can be expected that this will increase and a wider range of smaller organisations run by people with disabilities and their families will emerge if given the space. These could be in a range of different forms from peer support groups to co-operatives for employing support workers, pay-roll services to information and training support groups.

Appendix 1

Definitions of disability in legislation

Definition in the DDA :

Disability, in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour;

and includes a disability that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future; or
- (k) is imputed to a person.

Disability Services Act WA 1993 definition of disability:

"disability" means a disability —

- (a) which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments;
- (b) which is permanent or likely to be permanent;
- (c) which may or may not be of a chronic or episodic nature; and
- (d) which results in —
 - (i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and
 - (ii) a need for continuing support services;

Appendix 2

Community Engagement examples

Australian Federal Government, Social Inclusion Website

<http://www.socialinclusion.gov.au/default.htm>

Australian Human Rights and Equal Opportunity Commission, Disability Rights Website

http://www.hreoc.gov.au/disability_rights/index.html

NSW Don't Dis my Ability campaign

<http://www.internationaldayofpeoplewithadisability.com.au/>

UK Leonard Cheshire Disability Rights, Creature Discomforts Campaign

<http://www.creaturediscomforts.org/>

UK Disability Rights Commission Youtube commercials

<http://www.youtube.com/user/DisabilityRightsComm>

UK Equal Opportunity and Human Rights Commission Equally Different Campaign

<http://www.equalityhumanrights.com/en/projects/equallydifferent/Pages/EquallyDifferent.aspx>

Victorian Disability Services Barnone Campaign

http://www.disability.vic.gov.au/dsonline/dssite.nsf/pages/barnone_moreinfoabout?open

Victorian Department of Human Services, Metroaccess and Ruralaccess

http://www.dhs.vic.gov.au/disability/building_better_communities/ruralaccess_and_metroaccess

WA Disability Services Commission, Count Us In

<http://www.disability.wa.gov.au/DSC:STANDARD:1189358996:pc=L3>

Accommodation and day activity examples

Australian Home and Community Care Program

<http://www6.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm>

WA Disability Services Commission, Accommodation Support

<http://www.disability.wa.gov.au/DSC:STANDARD:365662395:pc=L7C5C2C2C3>

Centre for Developmental Disability Studies, Active Support

http://www.cdds.med.usyd.edu.au/html/ActiveSupport/ActiveSupport_Workshop250306.html

WA Brightwater Group

<http://www.brightwatergroup.com/profile/index.php>

WA The Centre for Cerebral Palsy
<http://www.tccp.com.au/content.php?page=1>

USA Jay Nolan Community Services
<http://jaynolan.org/>

Australian support for disadvantaged jobseekers
<http://www.workplace.gov.au/workplace/Individual/DisadvantagedJobseekers/>

Australian Federal Government, Employment for people with disability
<http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-nav.htm>

Independent and supported living examples

Supported living website, Information site by Family Advocacy and Multicultural Disability Advocacy Association in NSW
<http://www.supportedliving.org.au/resources/index.html>

One by One, Family governed group in Victoria
http://www.onebyone.org.au/index.php?option=com_frontpage&Itemid=1

Homes West, Queensland
<http://www.homeswest.org.au/>

My Place, WA
<http://www.myplace.org.au/welcome/index.html>

Community Living Project, SA
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