HEALTHYdesign | **Griffith** UNIVERSITY

LITERATURE REVIEW

Self-directed Support: A state, national and international understanding

2013

A university/industry partnership:

Griffith Health Institute: Community Science Research Program

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Contact Details

Associate Professor Heidi Muenchberger
Griffith Health Institute
Community Science Research Program
Griffith University
E| h.muenchberger@griffith.edu.au
www.griffith.edu.au

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1.0 BACKGROUND

Person-centred practice is now central to most human service delivery environments and professions and generally refers to support "that is respectful of and responsive to [individual] preferences, needs, values and ensuring that [the person's] values guide all decisions" (Corrigan, Donaldson, Kohn, Maguire, & Pike, 2001 p. 6). Person-centeredness can be traced back to the disability *community or independent living movement* (Gloag, 1985) and further back to *normalisation* (Nirje, 1985) and *Social Role Valorisation* (Wolfensberger, 1998). The accumulation of these movements, frameworks and service delivery approaches has informed the current policy and practice paradigm of *'self-direction'*. In this document we use the term *self-direction* in accordance with current Queensland government articulation:

> "Self-directed support is an approach which enables people with a disability and/or their family to have choice and control over their disability supports and services to achieve positive outcomes in their lives. By using funding and other resources to plan, purchase and select supports and services that suit individualised needs, people with a disability and/or their families become active participants in the design and delivery of their disability support" (The State of Queensland, 2012 p. 3).

Self-direction identifies four core elements: 1) participant control, 2) participant responsibility, 3) participant a choice and 4) avoidance of conflict of interest (Cook et al., 2010). In essence it is about handing more control and responsibility over to individual service users[1]. Self-direction could be seen as the next step in the implementation of personalised approaches, enabling individuals' better choice, control and empowerment than ever before. The self-direction movement advances these critical personalisation concepts and actively promotes a person's ultimate control over most if not all aspects of their care and support, including financial management.

Notions of self-direction are now adopted in a range of health care services and professions, such as those focused on *disease management* and *chronic illness* and are enacted through concepts and practices such as *self-manage*ment. In the United States the economic rationalist imperative has driven *Consumer Directed Health Care Plans (CDHCP)* as a valid option in the health insurance landscape, which closely mimic self-direction as applied to the disability arena in the United States.

The following literature review seeks to articulate the **international and national evidence** in relation to self-direction, particularly focusing on people with a disability. We begin this review by

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[1] Service users refers to the 'client' or 'participant' of services provided.

describing the current research context and the policy context within Australia in relation to self-direction. After this we define and articulate the array of responses to self-direction including the challenges and benefits of self-direction, particularly as it relates to a vulnerable population of people who may not have the skills to undertake self-direction and those individuals who may be competent but have no desire to undertake self-direction (this may include *surrogate* decision makers and *service-users*). Finally, we consider skills development in terms of self-direction.

A glossary of terms is supplied (see Appendix A), with preferred terminologies for this context.

2.0 RESEARCH CONTEXT

2.1 COMMISSIONED RESEARCH

In 2012 Griffith University was the successful recipient of the Endeavour Foundation Endowment Challenge Fund (EFECF) to conduct research expanding on existing work at Griffith University focusing on *support coordination*, long-term disability, *peer-led* programs of support and self-voice in relation to people with complex support needs. Preliminary work on developing a comprehensive evidence base of service and support coordination for people with high and complex health needs has been undertaken (Harris, Muenchberger, & Erhlich, 2012). Researchers at Griffith University have earlier confirmed the important role of significant others (e.g., family and friends) and paid carers in providing meaningful navigation of an individual's support needs (see Kendall, 1996; Muenchberger, Kendall, & Han, 2010; Muenchberger, Kendall, & Neal, 2008). However, significant others and service users with cognitive disabilities (including intellectual disability and brain injury) remain under-recognised in the formal delivery of coordination of supports and services, and continue to report a lack of appropriate supports to enable them to continue their full or partial participation in future service coordination.

2.2 RESEARCH AIM

The **aim** of the research is to consult with adults with *cognitive disabilities*, their families and key support staff to:

1) explore current support processes,

2) articulate desires and motivations to undertake self-direction,

3) define the skills required to undertake self-direction, and

4) develop a self-direction skills package for service users.

The skills package will be embedded in best practice, be measurable and offer a range of tools that could be used or adapted by service providers or individuals. Crucially, the development of the package will involve input and feedback from *service users* to ensure their needs are met. At project completion, Endeavour Foundation will be provided with a preliminary skills package that can be applied retrospectively or in forward planning in any supported accommodation setting and will enable NDIS (National Disability Insurance Scheme) readiness in relation to people with cognitive disabilities and their families/carers.

2.3 RESEARCH ORGANISATIONAL CONTEXT

Endeavour Foundation is the largest not-for profit community disability service provider in Australia, supporting over 3000 people across QLD and NSW. The Foundation was established in 1951 by a group of concerned parents who wanted to provide educational opportunities for their children with intellectual disabilities. The organization aims "to provide opportunities for people with a disability so they may participate in the everyday life of the community" through a range of services and supports including: accommodation; aged support; children-focused services; employment opportunities; education program in literacy; technology and social skills; and lifestyle opportunities. Within the current research, adults with a cognitive disability, who are served by the organisation in will be invited to participate.

It is important to note that the workforce is predominately *non-professionalized* (i.e. not led by a specific discipline or approach) and often delivered by non-qualified frontline *support workers*. Some of the issues facing the service users population include challenges with behavior, *activities of daily living (ADL)* such as personal care and *independent activities of daily living* (IADL) accessing typical community events and activities (employment, education, recreation, public transport, financial management, medical appointments and so on). Many service users are without *unpaid relationships (carers)* or their parents are aging and support roles are being transitioned to siblings or other relatives who may not have had significant experiences with the service system.

2.4 RESEARCH LOGIC

The research logic (i.e., theory of change) behind the current research and proposed intervention is outlined in the figure below. A logic model assists in defining the setting, assumptions and key variables that surround a particular issue or research problem, and highlighting service gaps and intervention strategies that may be possible.

Context:

The current national disability system is fragmented, broken and unable to respond in equitable and fair way to people with a disability and their families.

The interface of service delivery, housing models, building design and service users experience is important to understand in developing appropriate services.

The current national debate on disabilities is centred around the introduction and implementation of a National Disability Insurance Scheme (NDIS) which will ensure national equity and access to flexible and personalised service responses.

Self-direction is a viewed as an important component to a national disability insurance scheme.

Intervention:

Develop a self-direction skill enhancement package after extensive consultation with people with disabilities, their carers and families, and staff who work alongside people with a disability.

PROBLEM: People with disabilities and/or their families and carers can and are often willing to coordinate their own support arrangements. However, service structures and individual skill competency can prevent this occurring in a seamless fashion.

Community Needs:

Inclusive and enabling communities that welcome diversity and deliver responsive services create a vibrant, healthy, efficient and equitable place for all members of the community.

Desired Outcome:

People with a disability and/or their families are active participants in the community and their services. Support needs, where desired, are met by individuals themselves who are armed with skills and knowledge to do so.

Assumptions:

- People with high and complex needs and their families, are capable of determining what is best for themselves.
- Services work alongside people to achieve the best outcomes.
- To achieve a fulfilling life people need to be able to fulfil needs at a biological, psychological and social level (bio-psycho-social)
- Families, friends and carers play a key role in supporting people to pursue their life goals.
- People with high and complex support needs may require services to assist in fulfilment of a range of life goals.
- Human rights concepts underpin any approach to working with vulnerable people.
- Principles of personalisation; individual needs; self-determination; relationships centred and meaningful life roles are important when working with vulnerable people.
- Disability is a social construct
- The level of desire to self-direct and depth of self-direction involvement, varies from individual to individual.
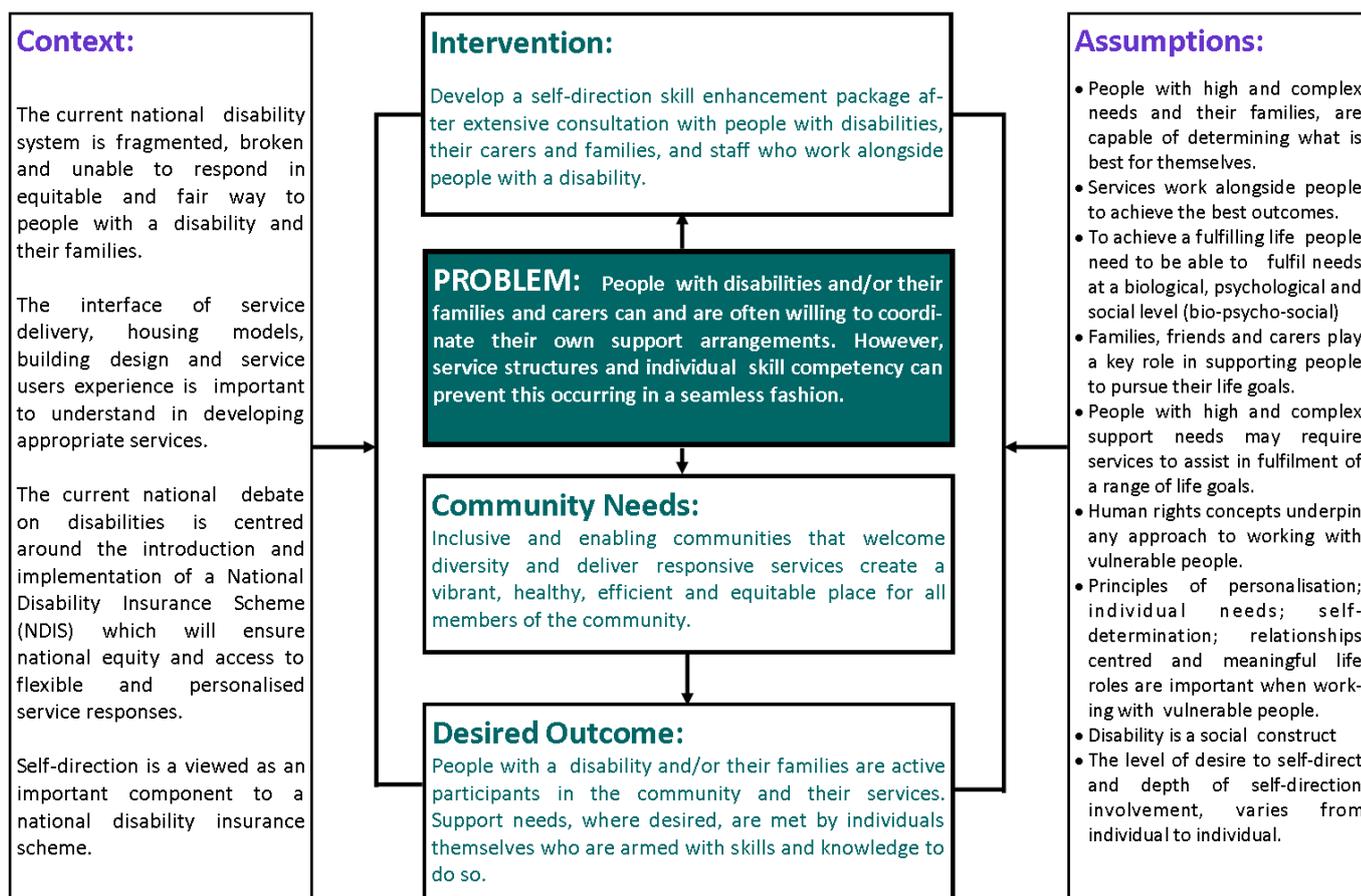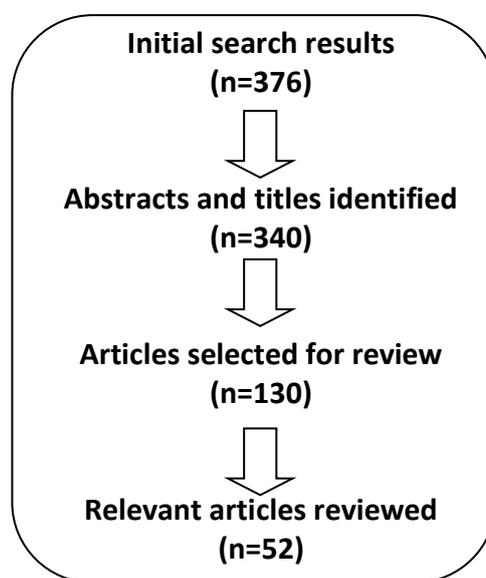
FIGURE 1 SELF-DIRECTION RESEARCH LOGIC

2.5 LITERATURE REVIEW: METHOD

The literature review is the first step taken to systematically identify knowledge gaps and inform future research directions. A comprehensive systematic literature search was conducted as outlined in Figure 2 to ensure, in the first instance, that peer-reviewed literature from the last 10 years was sourced. Additional literature was located from references mentioned in existing articles and from grey literature related to the topic.

Systematic peer reviewed literature search

The search terms client-led care, self-directed care and consumer-directed care were the terms used to search three data bases: science direct; Medline; and CINALH (Cumulative Index of Nursing and Allied Health). A list of exclusion (e.g. health insurance, health specific conditions/populations) and inclusion criteria were used by two researchers to independently select articles based on abstract and title reading. The full list of titles selected by the researchers was merged and a second round of article selection occurred. The minor variance on the second round was discussed until inclusion or exclusion was agreed. Systematic literature search results are in Figure 2.

Initial search results
(n=376)

Abstracts and titles identified
(n=340)

Articles selected for review
(n=130)

Relevant articles reviewed
(n=52)

FIGURE 2 SYSTEMATIC LITERATURE SEARCH

The following section provides a summary of the literature on state, national and international approaches to self-direction.

3.0 LITERATURE REVIEW: SELF-DIRECTED SUPPORT

3.1 MODELS OF SELF-DIRECTION

While the general aim of self-directed models of support is to provide service users with greater choice and control, self-directed support initiatives can vary in the level of independence, choice and

control they offer (Cook et al., 2010; Kim, White, & Fox, 2006; Low, Chilko, Gresham, Barter, & Brodaty, 2012). Programs also differ in the amount of support delivered from service providers, in terms of service coordination, organisational management and financial administration. The literature and reports of existing programs and strategies identify three broad approaches; 1) the *traditional agency-directed approach, 2) a combination of case management and self-direction and 3) an entirely service user directed approach* (Adelman, Kitchener, Ng, & Harrington, 2012; Kim et al., 2006; Kodner, 2003; Putnam, Pickard, Rodriguez, & Shear, 2010).

The traditional agency-directed approach involves no self-direction (Low et al., 2012). Service providers select and manage the service based on assessment of the individual's needs, with little or no input from the service user. Service users may be asked for their input on the scheduling of the services they are to receive, however this decision and other decisions regarding services and employees are ultimately made by the agency representative (Sciegaj, Capitman, & Kyriacou, 2004).

The second approach involves a combination of case management or assistance from agencies and self-direction. An example of this would be an approach where the service users and their agency decide on services and scheduling together, however the responsibility of organising and paying for the chosen services remains with the agency (Sciegaj et al., 2004).

Finally, there is the entirely self-directed approach in which service users are given control over the recruitment of staff (e.g., attendant carers) and the purchase of goods and services relevant to their needs (Low et al., 2012). The most flexible of the self-directed models is sometimes described as an 'open' model in which service users are given a cash payment and complete discretion over how to spend this (Alakeson, 2010). In this model, support funds do not have to be acquitted, however if an agency review (conducted approximately every 3 to 6 months) finds that the support being received is not sufficient, the allowance is withdrawn and services will be subsequently provided by an agency. Alternatively, in the 'budget' or 'planned' model, individual budgets are calculated based on a selected formula. Service users then go through the process of identifying their needs and goals and select goods and services to suit their individual requirements without exceeding their given budget. This model of self-directed support has more restrictions and is more closely monitored as plans are generally required to be approved by an agency or case manager and service users must record and account for their purchases. Within the self-directed approach, there are three main identified categories of expenditure: individual-directed goods and services, self-directed personal support, and self-directed skills development (Lombe, Mahoney, & Bekteshi, 2009).

In order to relieve service users of the additional administrative responsibilities that follow greater choice and control in employing support workers through a self-directed model, *Financial Management Services* (payroll agents, employer agents and fiscal intermediary organisations) are often used to take on the financial responsibilities associated with managing support services (Scherzer, Wong, & Newcomer, 2007). Some agencies take on the role of administering and accounting funds on behalf of people, whereas some programs, such as in the United States, clearly articulate that an agency cannot be involved in financial management for self-directed programs if they are involved in service delivery to overcome issues of undue influence (Cook et al., 2010). Three basic approaches to fiscal management in self-directed programs are articulated by Scherser, et al., 2007 as, *Fiscal/Employer Agent, Agency with Choice, and Public Authority*. The following table describes these approaches.

TABLE 1 OVERVIEW OF FISCAL MANAGEMENT SYSTEM MODELS (SCHERSER, ET AL., 2007)

FMS Approach	Typical Organization	Employment Relationship(s)	FMS Employer-Related Fiscal and Administrative Functions
Fiscal/employer agent	Bookkeeping/payroll service, information technology company	Recipient is common law employer of the PAS worker ("independent provider"). FMS is employer agent for fiscal employer tasks. Recipient is responsible for recruiting, hiring, training, supervising, firing worker.	Process hiring paperwork, conduct background checks, process timesheets, disburse paychecks, manage federal and state employment taxes, unemployment insurance, workers' compensation
Agency with choice	Center for Independent Living, homecare or home health care agency	Agency is common law employer of PAS worker. Recipient is the "managing employer" responsible for recruiting, selecting, training, supervising worker-but may be assisted by Agency.	Same as above
Public authority	Independent quasi-governmental entity	Recipient is common law employer of the PAS worker ("independent provider"). Recipient is responsible for recruiting, hiring, training, supervising, firing worker. Public Authority may be the Employer of Record for purposes of collective bargaining.	Employer-related tasks dispersed among state and county offices and departments.

Other authors (e.g. Lombe et al., 2009) discuss the notion of capacity building in relation to people with a disability who take on self-direction. The *credit union model* is one capacity building model that has been utilised in trials of the cash and counseling program in the United States. This model is

able to provide fiscal tasks such as deposits, tracking, distribution, payroll, invoice payment as well as providing training services (Lombe et al., 2009). In another example of *fiscal intermediary* involvement was one self-directed program created a public-academic partnership where a university undertook the roll of billing withholding of money for payroll taxes (Cook et al., 2010).

3.2 SELF-DIRECTION: AUSTRALIA

As a preface to a discussion on self-direction it is critical to consider the historical and contemporary policy context. If we do not adequately understand where we have come from we are at risk of repeating past service delivery mistakes. In the same vein, if we do not adequately understand the contemporary policy and political context in operation, we are at risk of repeating what has already been addressed in the market place and will not offer anything new and innovative; further we are at risk of ignoring vital policy cues for future decision making (e.g. NDIS). The history of disability support in Australia forms the basis for current practice and is attached in **Appendix B**.

Over the past decade, the Queensland government has made a number of policy decisions that focus on improving the service delivery system and developing a social inclusion agenda. Perhaps the most significant of these directions was the introduction of the Quality System in 2004 (Queensland Goverment, 2005) where for the first time service providers had to undergo a rigorous quality assurance process to receive ongoing government funding. This was expanded in 2011 with the Growing Stronger Together initiative (Queensland Government, 2011b) aimed at improving the State disability system. At this time the government also introduced Absolutely Everybody (Queensland Government, 2011a) a 10 year plan to create inclusive communities in QLD. All of these policy directions coincide with the broader national agenda, in particular the National Disability Insurance and Injury Schemes and National Disability Standards (Department of Human Services Victoria, 2012).

In terms of self-direction in Queensland, in 2012 the state government released the "Your Life Your Choice: Self-directed support framework" (The State of Queensland, 2012). It is based on principles including autonomy, independence and the rights of people with a disability to make decisions regarding their own lives and aims to provide a framework for supporting people with disabilities and their families in self-directing their support. It advocates a model of self-directed support which allows individuals to choose a level of choice and control which suits them and their circumstances (see figure below). The level of self-direction also remains flexible, to allow for changes in

circumstances and needs or to give service users greater control once they have developed the skills and confidence to take on greater responsibilit.
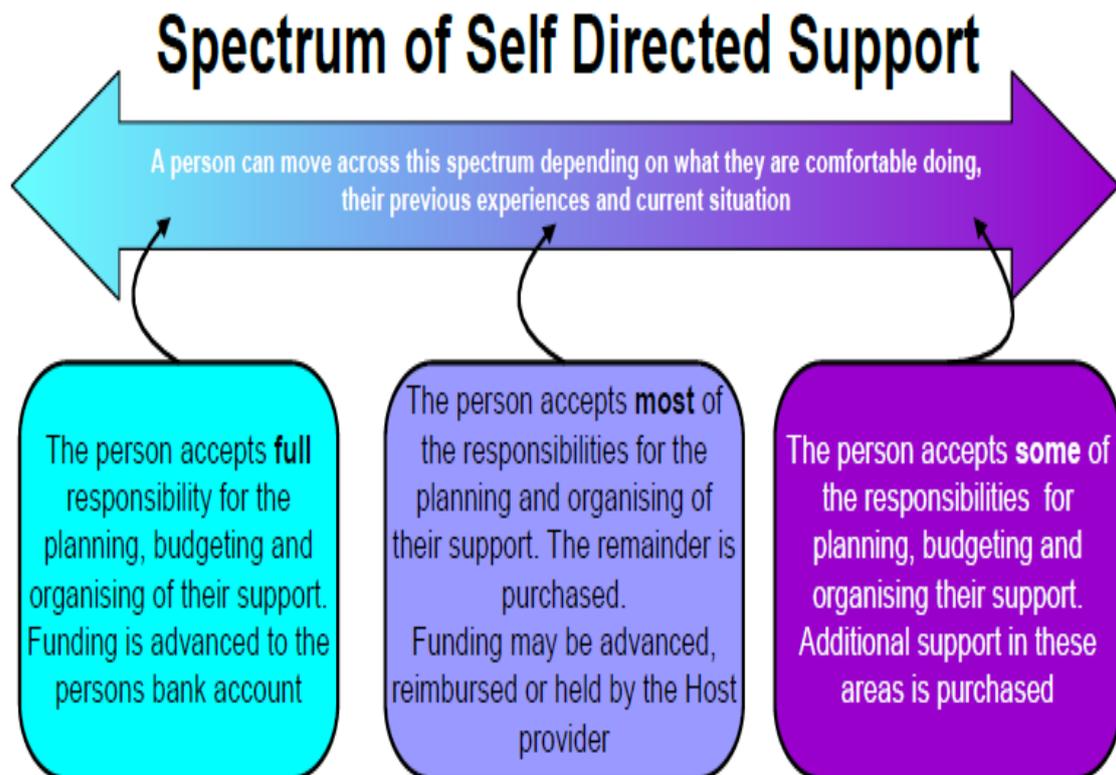
Spectrum of Self Directed Support

A person can move across this spectrum depending on what they are comfortable doing, their previous experiences and current situation

The person accepts **full** responsibility for the planning, budgeting and organising of their support. Funding is advanced to the persons bank account

The person accepts **most** of the responsibilities for the planning and organising of their support. The remainder is purchased. Funding may be advanced, reimbursed or held by the Host provider

The person accepts **some** of the responsibilities for planning, budgeting and organising their support. Additional support in these areas is purchased

FIGURE 3 SPRECTRUM OF SELF-DIRECTED SUPPORT (THE STATE OF QUEENSLAND, 2012)

In Australia today there is considerable momentum and movement in response to the 2011 Productivity Commission Report which stated that the disability sector was "underfunded, unfair, fragmented, and inefficient", (Productivity Commission, 2011 p.2). A key recommendation of the report was the introduction of a no fault national insurance scheme to provide cover for all Australians with a *significant* disability to pay for long term high quality care and support through "*reasonable and necessary*" supports (Productivity Commission, 2011 p.21). It was recommended that the scheme be funded by the Federal Government making payments into the National Disability Insurance Scheme (NDIS). Although it remains unclear how the scheme will work in practice, it is a focal point of discussion and has dictated the support and care agenda within Australia in recent times. Other key policy documents recently released in the disability landscape include the Draft National Disability Standards (Department of Human Services Victoria, 2012) and the National

Disability Strategy (Council of Australian Governments, 2011) . These reports indicate nationwide shift toward a more coherent approach between the various State and the Federal jurisdictions in terms of disability services.

While self-directed models of support have been operating formally in Australia since 1998 (Department of Health and Ageing, 2012), there is limited research available on these programs. In recent times, the Department of Health and Ageing introduced a pilot program for self-directed support for elderly people (Department of Health and Ageing, 2012). In 2010, 500 self-directed support packages were available to eligible participants who requested to be involved with the program. The program was relatively restricted in terms of the control service users were given, as even though they were able to choose the services they received and the employees that were hired, service providers were still responsible for ensuring the quality of services provided (e.g. conducting background checks on employees, managing the budget and bookkeeping) (Low et al., 2012). Additionally, service users were unable to hire family members or friends as paid workers (Low et al., 2012). The main types of support used by participants in the program included assistance with activities of daily living, domestic assistance, social support, nutrition, hydration and meal preparation and nursing care (Department of Health and Ageing, 2012). Results from the initial pilot program found no differences on a measure of wellbeing between the participants in the client-directed support program and a comparison group receiving standard support packages. However, participants, particularly those with high support needs including dementia reported an increase in satisfaction with their ability to participate in social and community activities, their social relationships and their health and wellbeing.

A longitudinal study conducted between 2003 and 2008 also evaluated a self-directed program for families with children with a disability in Melbourne (Ottmann, Laragy, & Haddon, 2009; Ottmann & Laragy, 2010). The families were all strong advocates of self-directed support and some had previous experience in managing funding packages (Ottmann et al., 2009). They were required to spend their budget on goods and services related to support needs and choose a service provider from an approved list. Program participants were also strongly encouraged not to hire family members unless there were exceptional circumstances. Most families chose not to take on the additional administrative responsibilities associated with self-directed support, electing instead to pay a fee to the host organisation to pay for this service (Ottmann et al., 2009). Results from the study indicated that there were benefits to both the program participants and their caregivers in terms of quality of life and support received. In particular the ability to hire support workers was identified as an important feature of the program by the families. However, the study also found

that caregivers reported feeling increasingly isolated over time. This highlights the importance of ensuring ongoing support and specific skills training/competency development are provided to caregivers to ensure they feel satisfied with the program and able to manage the added responsibilities of self-directed support packages.

3.3 SELF-DIRECTION: INTERNATIONAL LANDSCAPE

Several countries around the world have implemented self-directed support programs including Austria, Germany, the Netherlands, New Zealand, the United Kingdom and the United States (Alakeson, 2010; Kodner, 2003). The models of self-direction employed vary in the control and flexibility offered to service users and are subject to ongoing studies and evaluations in order to make adjustments to the programs to ensure their effectiveness and efficiency. One of the programs which gives service users a great deal of flexibility and control is the 'Cash and Counselling Demonstration and Evaluation' in the United States (Loughlin et al., 2004). Initially trialed in Florida, New Jersey and Arkansas in 1999, the **Cash and Counselling** program has since been expanded to include twelve additional states (Doty, Mahoney, & Sciegaj, 2010). Medicaid recipients in participating states were invited to express their interest in the program and were then randomly assigned to either the group which participated in the program or the group which continued to receive traditional service. Participants were given a monthly cash allowance the equivalent to expenditure on their support in the traditional agency-directed system (Loughlin et al., 2004; Mahoney, Desmond, Simon-Rusinowitz, Loughlin, & Squillace, 2002; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008) with which they could hire workers (including friends or family members, with the exception of the program in Arkansas, where service users were not able to hire their spouse or parents) and purchase goods and services or home renovations which supported their needs (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Consultants (also referred to as 'counsellors') were allocated to assist service users in planning and spending their monthly allowance. This role differs to the traditional case manager role because consultants provide service users with advice to assist them in their decisions rather than making recommendations or decisions themselves (Doty et al., 2010). Additionally, a representative such as a family member could be nominated by the service user to assist in the decision making process (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008), however this representative was not able to be employed by the recipient of the services in order to avoid a conflict of interest (Low et al., 2012).

The majority of participants in the program used their allowance to hire workers for assistance with personal care, routine health care needs such as taking medication, housework and transportation assistance (Barczyk & Lincove, 2010; Lombe et al., 2009). Studies comparing service users involved in the program to those receiving traditional assistance from Medicaid showed that service users given control over their own budgets reported greater satisfaction with support arrangements and fewer unmet needs (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Involvement in the program also appeared to have a positive impact on reported personal care and wellbeing (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Overall, the trials were deemed to be quite successful and this program and subsequent self-directed initiatives are believed to be appropriate for a range of people including elderly service users, non-elderly adults and children (with representatives) (Carlson, Foster, Dale, & Brown, 2007), people with mental health problems (Alakeson, 2007; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008; Shen, Smyer, Mahoney, Loughlin, et al., 2008) and people with physical disabilities (Barczyk & Lincove, 2010).

The **Individual Budgets Program** trialed in the United Kingdom also aimed to give service users greater choice and control over their support using a flexible model of self-direction (Low et al., 2012). Participants in this program were also randomly assigned to either the group involved in the program directing their own services or the control group who continued to receive agency-directed services. Those participating in the program were able to choose how they receive their allowance with options including direct payments, payments into joint accounts or having a local authority manage the money. Service users were supported in the planning and use of their budgets and a senior manager in the program was required to assess and approve the plan before money could be spent. Evaluations of this program have shown that there were some differences in outcomes for service users within in each group (Glendinning et al., 2008). Service users in the program with mental health problems reported higher quality of life compared to those not involved in the program. Adults with physical disabilities reported greater satisfaction with their support and higher quality of support compared to those receiving traditional services and people with learning disabilities were more likely to report that they felt in control of their lives compared to the control group. Interestingly, older adults managing their own budgets reported lower psychological wellbeing than those in the control group, a finding which is suspected to be due to the increased burden felt by those in charge of planning and organising their own support. These examples of overseas self-directed support programs appear to be more flexible and less restricted than the programs tested in Australia.

3.4 CHALLENGES IN SELF-DIRECTION

In discussing self-direction, it is important to acknowledge the challenges of implementing such an approach, particularly as it relates to a vulnerable population, and there is no single approach found to be most effective in enabling service user choice, control and independence. A key issue often raised is the ability of service users to spend their allowance appropriately. This includes concerns that service users may misuse funds or spend them fraudulently (Adelman et al., 2012), or that service users, particularly those with cognitive impairments may not have to capacity to manage their budget effectively and ensure adequate support is provided (Adams & Drake, 2006; Alakeson, 2008; Alakeson, 2010). Self-direct support programs have chosen to manage this issue in a number of ways to date. For instance, in the past, the Direct Payments Program in the United Kingdom excluded people who were unable to manage their own budget or people who were deemed unsuitable to be managing their own budgets, including people with significant cognitive impairments (Duffy, 2007a). The eligibility criteria for the Individualised Funding scheme in New Zealand requires individuals intending to manage their own services to undergo assessment and agree to training in relevant skills such as managing staff (Ministry of Health, 2003). Some programs in the United States have a specific requirement as to what percentage of their allowance a service user must put towards traditional services and how much can be spent on alternative services, to ensure that important services are being received (Cook, Russell, Grey, & Jonikas, 2008). Alternatively, many programs allow service users to nominate a *representative* (*surrogate*) to assist them in the decision-making process or make decisions on their behalf (Duffy, 2007a; Kodner, 2003; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). In particular, this was found to be a suitable options for those with cognitive and developmental disabilities who experienced difficulty in managing their budgets independently, as they were still able to benefit from being able to express their personal preferences in regards to their support and the flexibility that self-direction allows (Mahoney, Fishman, Doty, & Squillace, 2007).

Even if service users are capable of directing their own support, they may not want this additional responsibility: competency does not equal capacity or desire. People differ in their interest in directing their own support or the support received by the person they are caring for (Alakeson, 2007; Duffy, 2007a; Mahoney, Simon-Rusinowitz, Loughlin, Desmond, & Squillace, 2004; Olinzock, 2004; Putnam et al., 2010; Sciegaj et al., 2004) and their readiness to do so (Olinzock, 2004). Additionally, their preferences may change over time (Putnam et al., 2010; Queensland Government, 2012). Therefore it is important that self-directed models of support can accommodate for a range of people and the level of control over their support that they are willing and able to take (Duffy, 2007a).

The potential for intended or unintended exploitation in a model of support which does not allow for the same level of monitoring of services by an agency has been raised as a concern within the self-directed support literature (Adelman et al., 2012; Matthias & Benjamin, 2003). Balancing the desire for greater control and self-management with ensuring that safeguards against abuse can be put into place is a key issue which must be considered in the design of future self-directed models of support (Fyson, 2009). However the concern that people might be at greater risk in self-directed models of support is not supported by evidence which suggests that very few cases of physical abuse or neglect have been reported by service users involved in self-directed support programs (Young & Sikma, 2003). Further, it has been shown that service users under self-direction are no more likely than service users receiving agency-directed support to report abuse (Matthias & Benjamin, 2003). Reports of financial abuse are also rare (Alakeson, 2010; Low et al., 2012). Additionally, models such as the one tested in Australia for aged care packages which require a service provider to manage the allowance provide a way to check that budgets are not being misused (Low et al., 2012). Similarly, requirements built into programs such as the process of having budgets approved, ongoing assessments of budgets and spending and the requirement of having to provide receipts for purchases all assist in monitoring the use of allowances to ensure they are being used appropriately (Alakeson, 2007). A likely conclusion from these findings is that people genuinely need their services and do not want to jeopardise the support that they have access to.

The transition from agency-directed support to self-directed support could be challenging for some service providers and professionals, as the changes may require some changes to philosophies and roles (Adams & Drake, 2006; Doty et al., 2010; Duffy, 2007a). For example, the role of a case manager changes to a more advisory role, allowing the service user to take on the leadership role and make decision regarding their support (Barczyk & Lincove, 2010). Many professionals in the field report concern over how to find the correct balance between empowering service users and giving them more control while also meeting their duty of care and responsibility to ensure that service users are receiving suitable, adequate support (Department of Health and Ageing, 2012, Fox & Kim, 2004; Young & Sikma, 2003). The evaluation of the Australian self-directed aged care packages identified the need for more guidance and support to be provided by government departments to service providers during the implementation of future self-directed support packages and the establishment of new practices to address this issue. Training for providers on how best to encourage and assist service users to take on a larger role in directing their services has also been identified as important (Davis, Cornman, Lane, & Patton, 2005; Deparament of Health and Ageing, 2012; Glendinning et al., 2008).

Additional support and information has also been identified as an important issue for family caregivers who may be making decisions on behalf of a family member (Putnam et al., 2010). Caregivers who had a family member enrolled in the Cash and Counselling programs in Arkansas reported less physical, emotional and financial strain than caregivers involved in traditional agency-directed support (Foster, Brown, Phillips, & Carlson, 2005). This may be due to the use of allowances to employ a worker to reduce their workload, thereby reducing some of the pressure felt by caregivers. However, as demonstrated in the longitudinal study conducted on the Melbourne self-directed support trial, despite enthusiasm and satisfaction with the program there is the potential for caregivers to feel increasingly isolated as time progresses if adequate supports are not put in place (Ottmann et al., 2009). Research has found that family caregivers may be emotionally and practically underprepared for the task of organising support services and that feeling prepared predicted higher levels of satisfaction with caregiving work (Kietzman, Benjamin, & Matthias, 2008). Therefore, adequate preparation and support for caregivers over a longer period of time appears to be important for ensuring that satisfaction and continued involvement in self-directed models remains high.

Challenges in self-directed support also exist in terms of finding and hiring staff. Research based on United States self-directed programs suggests that employing workers was a key challenge for many participants, given the shortage of workers available and willing to take on such a role, especially in programs which did not allow service users to hire family members (Doty et al., 2010; Grossman, Kitchener, Mullan, & Harrington, 2007; Low et al., 2012; Young & Sikma, 2003). The hiring of family members, particularly immediate family remains a controversial issue, as there are concerns that it creates the potential for a conflict of interest or may increase the likelihood of abuse against more vulnerable service users (Barczyk & Lincove, 2010). However, in addition to the convenience of being able to hire family as paid carers, studies have shown that there are benefits to health and quality of life (Barczyk & Lincove, 2010) and that service users who hired family members reported experiencing greater stability of support, greater satisfaction with their relationship with their carer and reduced feelings of risk compared to those who hired friends or had no previous relationship with the employee (Matthias & Benjamin, 2008). Many service users also believe that they should be able to hire family members including parents and spouses (Grossman et al., 2007) and cite the ability to pay a family member for the support that they provide as a key reason for being interested in a self-directed model of support (Mahoney et al., 2004). Individualised Funding schemes in New Zealand have not allowed family members or caregivers living in the same home as the service user to be paid for their work, however feedback from participants indicates that they would prefer this restriction to be removed to allow for greater flexibility (Bennett & Bijoux Limited, 2009). Changes to

this restriction are likely, as new policies are currently being developed in response to the recent decision by the Court of Appeal to uphold the High Court ruling that the New Zealand Ministry of Health's policy of not paying family members for their work as carers is a form of discrimination (Court of Appeal of New Zealand, 2012). Australian programs have so far discouraged service users from hiring family members and the impact of this policy is not yet known (Low et al., 2012).

Interest also surrounds the issue of how cost effective self-directed programs would be and how they would compare to the cost of agency-directed services. Initial concern that participants may overspend their budgets have been alleviated by results of pilot programs showing that many service users spend less than their allocated allowance (Alakeson, 2007; Barczyk & Lincove, 2010; Cook et al., 2008). It is also suggested that allowing service users to choose and control their own support will be cost effective as they are in the best position to know their own values, preferences and goals, thereby reducing the chance that services or supports ineffective for that individual will be purchased (Adams & Drake, 2006; Duffy, 2007b). Results of financial comparisons between the models of support tend to find that self-directed services are more expensive than agency-directed services (Alakeson, 2010, Barrczyk & Lincove, 2010, Mahoney & Sciegaj, 2010). This was partly attributed to the fact that individuals involved in self-directed programs received the full amount of personal care that they were entitled to, whereas service users receiving agency-directed support did not (Alakeson, 2010). However, this increase in spending on personal care assistance had other economic benefits, with long term analysis indicating a subsequent reduction in nursing home use (Alakeson, 2010). It is also worth noting that the private health insurance sector in the US has commenced the use of *Consumer Directed Health Care Plans* (CDHCP). A conclusion that can be drawn from this spreading movement into the private sector is that it appears more cost effective and efficient for individuals to control how their money is spent, although further research is needed in this emerging area.

3.5 BENEFITS OF SELF-DIRECTED MODELS OF SUPPORT

Research conducted on existing self-directed models of support and existing self-directed support programs identify a number of benefits of adopting models which allow greater service user choice and control. Self-directed models represents *a more respectful approach* to assisting people with disabilities, aiming to empower service users by focusing on their strengths, goals and abilities rather than focusing on illness or disability (Barczyk & Lincove, 2010; Duffy, 2007a). It also allows service

users to develop a sense of control (Barczyk & Lincove, 2010) and the opportunity for greater self-determination, which has consistently been linked to improved quality of life (Lachapelle et al., 2005; McDougall, Evans, & Baldwin, 2010 Wehmeyer & Schwartz, 1998).

The shift towards self-directed models of support also reflects the desire for greater independence from community-based services, and consequently control over their lives, reported by a number for service users (Barczyk & Lincove, 2010; Mahoney et al., 2002; Mahoney et al., 2004). Research indicates that both service users and their caregivers, including carers of children with disabilities, are interested in having more input into the decision-making process and coordination or day to day organisation of services (Loughlin et al., 2004; Putnam et al., 2010). Unsurprisingly, self-directed support is of particular interest to those who are unsatisfied with the services they are currently receiving or believe that there are needs which are not being met (Department of Health and Ageing, 2012, Loughlin et al, 2004, Mahoney et al., 2002,). There are some reports that elderly people are less likely to be interested in directing their own services than younger people, however preferences in all age groups vary in the preferred model of support and the degree to which they would like control over their support (Adams & Drake, 2006; Sciegaj et al., 2004) or the support of the person they are caring for (Putnam et al., 2010). Overall, service users have indicated a strong preference for self-directed models of support (Gray et al., 2009; Grossman et al., 2007) and regardless of the level of control people preferred, individuals believed that they should be able to make a choice as to which model their service provision would come under and the level of independence they would have (Putnam et al., 2010).

Service users also report high levels of satisfaction with self-directed services (Cook et al., 2008; Kim et al., 2006; Young & Sikma, 2003). Increases in satisfaction with support have been reported after changing from agency-directed services to self-directed models of support (Alakeson, 2008; Alakeson, 2010; Gray et al., 2009; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Additionally, comparisons of service users directing their own services and those receiving agency-directed services demonstrate that those involved in self-directed services report greater satisfaction with the availability of services and the services they received (Carlson et al., 2007; Cook et al., 2008), progress towards their personal goals (Cook et al., 2008) and were more likely to feel that their needs were being met (Alakeson, 2007). Cultural issues were also suggested to play a role in satisfaction with self-directed programs, with the flexibility and greater choice and control over support workers being identified as important by people from culturally and linguistically diverse backgrounds (Barczyk & Lincove, 2012; Department of Health and Ageing, 2012).

Self-direction has also increased access to quality services for many service users (Alakeson, 2010). Hiring family and friends as carers resulted in an increased number of hours of services received, with participants receiving the full number of hours of personal care allocated, whereas service users receiving traditional services often do not use all of the hours allocated due to difficulty finding staff (Alakeson, 2010). The support provided under self-directed model has been found to be the same quality as support provided under agency-directed models, despite the reduced ability of agencies to monitor the support and ensure that it remains of a high quality (Gray et al., 2009; Kim et al., 2006; Young & Sikma, 2003). Some reports have even indicated more positive health outcomes resulting from self-directed models (Cook et al., 2008; Shen, Smyer, Mahoney, Loughlin, et al., 2008), including fewer unmet needs compared to service users receiving agency-directed services (Carlson et al., 2007).

3.6 SKILL DEVELOPMENT IN SELF-DIRECTION

People differ in their interest in directing their own services and the components of their support that they would like control over (Sciegaj et al., 2004) and it is important for service users to be able to decide on a model of support that suits them. However, it is also important that service users who do express interest have the skills or are assisted in developing the skills necessary to effectively direct and manage their own support. Information and educational services are vital to ensuring that service users have the ability to make informed decisions and implement decision regarding their services (Kodner, 2003). The need for training and assistance has been identified by service users eligible for participation in self-directed support programs (Mahoney et al., 2004). Participants indicated a need for training in finding a worker (62.6% of respondents), interviewing a worker (54.6%), conducting a background check on potential employees (74.0%), deciding on pay (76.3%), firing a worker (51.2%), help with payroll (76.0%) and training to provide knowledge on what to do when a paid worker does not show up (69.4%). Some programs, such as the Individualised Funding scheme in New Zealand have also recognised these needs and require program participants to undergo training in budget management and a number of skills necessary for being an employer such as remittance of taxes (Ministry of Health, 2003).

Despite the importance of ensuring adequate skills and training in self-direction, little research has been conducted on the skills required and there are no guidelines as to the skills most important for service users to learn. Four general competencies for self-directed support management and

coordination can be identified; planning, accessing/purchasing, organising/coordinating and acquitting (with a host organisation or fiscal intermediary).

Two strategies used to promote shared decision-making between service users and practitioners (health care setting) were identified by Adams & Drake, (2006) as:

1. Communication training for service users and clinicians- to focus on building a better relationship and more effective communication
2. Decision aids (also discussed in Deen et al., 2012)

Skills in these areas will obviously facilitate self-direction models of support. Other research has identified a range of skills that are required for self-direction (Central Emergency Network, in Edney, Mallia, & Farrell-Renwick, 2002) including:

- Ability to assess own needs
- Having the knowledge necessary to instruct personal staff in personal care routine
- Understanding and communicating relevant information about disability and physical functioning
- Developing and maintaining effective working relationships
- Directing adults with differing values and learning ability
- Knowing the time required for support routines
- Organising and carrying out tasks efficiently
- Accepting outcomes as being related, in general, to quality of directions
- Making a reasonable work environment
- Recognising and respecting parameters of service
- Solving conflicts with staff
- Being assertive in order to get one's needs met, versus an aggressive or passive approach

Integrating this body research with the knowledge obtained from participants in the Endeavour Foundation research project will enable the development of an evidence based and relevant skills package to for this organisational context and service user population.

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APPENDIX A: GLOSSARY OF TERMS

TERM	ALTERNATIVE TERMS	DEFINITION
Activities of daily living (ADL)	Personal Care	e.g. eating, bathing, bladder and bowel requirements, dressing, walking (Adelman et al., 2012) (See also Instrumental Activities of Daily Living)
Agency-directed care	Traditional services Traditional case-management model Agency-based services Case management	Typical or traditional agency based services who procure funds and deliver services to people as assessed.
Capacity		"the person can understand the choices available to them and the consequences of these choices (for both themselves and others) and is able to communicate the decision to others" (Queensland Government, 2012)
Consumer Directed Health Care Plan	CDHCP	USA health insurance scheme program where some insurances allow participants to select their services and providers.
Coordination	Case management Care coordination Support	"The process of supporting people who require service assistance, within the principles of personalisation, with a seamless and coherent service experience that responds to their prioritised individual needs within available resources" (Harris, Muenchberger, & Ehrlich, 2012). "activities performed to ensure that multiple parties to the delivery of health and disability care work together to deliver the needed services, drugs and equipment" (Hwang et al., 2009) (see also *support*)
Coordinator	Case manager Key worker Lifestyle worker Care Coordinator Counselor Support broker Consultant Counsellor Recovery coaches (Cook et al., 2008) Life/recovery coach (Florida SDC program) Resource broker	Paid person involved in facilitating and/or support and care needs. Provide advice and support to consumers in planning and monitoring of services and may assist them in organising the service they choose (Doty et al., 2010), however they do not make decisions or taken any action not decided upon by the consumer (Cook et al., 2010) (See also *support worker*)
Cognitive disabilities	Intellectual disability Learning Disability Sensory Disability Acquired Brain Injury Traumatic Brain Injury Mental Illness	Term used to describe a range of disabilities and impairments that impact on person in terms of daily living needs.
Community Living Movement	Independent Living Movement	The movement behind the closing or scaling down of large scale institutional settings.
Decision aids		"designed to assist patients in understanding their health care choices" (Deen et al., 2012) "Decision aids are information interventions that help service users to understand the pros and cons of a medical decision and may also include exercises to help the service user clarify their own values and preferences. They can be self-administered or used with a practitioner" (Adams & Drake, 2006)
Financial management services	Fiscal intermediary Fiscal/Employer Agent:	"provide service such as provider billing and withholding money for payroll taxes" (Cook et al., 2010) "handles the empower-related fiscal and administrative tasks, such as social security and tax withholding from workers paychecks, paying and filing employment taxes, and enrolling recipients in workers

TERM	ALTERNATIVE TERMS	DEFINITION
		compensation insurance" (Scherzer, et al., 2007, p77)
	Agency with Choice:	"handles the employer-related fiscal and administration tasks. The recipient is the co employer responsible for selecting, directing and firing workers" (Scherzer, et al., 2007, p24) "independent government entity that supports recipients by managing a worker registry and offering training opportunities to both recipients and works" fiscal tasks are undertaken by a third entity in this model (Scherzer, et al., 2007, p235)
	Public Authority:	"provides specialized supports such as management of a participants public funds deposits, tracking, and distribution…Administers payroll, handles invoice payments and provides training services" (Lombe et al., 2009 p22).
	Credit union model:	Credit union involvement in financial management and skills development.
Health literacy		"the degree to which individuals have the capacity to obtain, process and understand basic health decisions" Institute of Medicine, in Lee et al., 2012
High and complex support needs	High and complex care needs Challenging behaviors	People who require complex support with activities of daily living and community participation. Could be some with a high and complex medical need or high and complex behavioral need.
Independent Activities of Daily Living		e.g. preparing meals, assisting with medication and shopping for groceries (Adelman et al., 2012)
Individualised Funding	Individual budgets Adult Lifestyle Packages Family Support Program	Funding that is attached to an individual person (government level) and not part of a block grant. However, organisations can indivdiualise block grants through internal mechanisms.
Model of support	Model of care Processes of care Delivery models Frameworks	A whole system of responses to a specific population of people through an evidence based approach (Harris, et al., 2012)
Non-professionalised	Support Worker	Workforce that is not led or driven by a specific discipline such as nursing or social work (see also support worker)
Normalisation		"making available to all persons with disabilities or other handicapts, patterns of life and conditions of everyday living which are as close as possible or indeed the same as the regular circumstances and ways of life as society" (Nirje, 1985)
Patient activation		"Refers to a person"s ability and inclination to manage their health and healthcare". "Patient activation can be viewed on a continuum from not activated (passive) to fully activated. Highly activated patients take more responsibility and acquire knowledge and skills that promote self-management and better decision-making" (Deen et al., 2012)
Patient engagement		"includes preparing for appointments, exchanging relevant information with clinicians, sharing decision-making and adherence to agreed upon plans of care" (Hochhalter, Song, Rush, Sklar, & Stevens, 2010)
Person-centred	Patient-centred Client-centred (also family-centred, relationship-centred, organisation-centred etc)	Patient-centred care: "care that is respectful of and responsive to individual patient preferences, needs, values and ensuring that patient values guide all clinical decisions" (Corrigan et al, 2003) Patient-centred model: "patients become active participants in their own care and receive services designed on their individual needs and preferences" (Palsbo & Dejong, 2003). "Client-centre health care involves the practitioner in exploring with the client his or her personal experience of illness, values regarding autonomy, risk, treatment, and outcomes and preferences for being involved in decision-making (Stewart and Brown, 2001 as cited in Adams & Drake, 2006) "it also shifts practitioners away from paternalistic decision-making, based on the assumption that clients are the best judges of their own needs (Adams & Drake, 2006)

TERM	ALTERNATIVE TERMS	DEFINITION
Self-care		"includes implementing healthy lifestyle choices- such as adopting a healthy diet, exercising and avoiding smoking- and managing specific chronic illnesses such as diabetes or bipolar disorder"(LaBrie et al., 2007).
Self-direction	Self-directed care Self-directed support Consumer-directed care Consumer-directed support Consumer-directed health care "money follows the person" model of care Client-led care	Programs of support where the person is actively engaged in their support arrangement depending on competency and motivation. "a range of service delivery models that place greater emphasis on consumer involvement including peer support services and consumer-run services" "self-directed care is based on giving each consumer control of an individual budget with which to purchase goods and services to meet his or her needs in place of or in addition to receiving directly provided services" (Alakeson, 2008) Encompasses both self-care and self-management (Knighton, 2009) "an alternative way of delivering services that seeks to empower participants by expanding their degree of choice and control in selecting services" (Alakson 2010) "designed to maximise the autonomy and independence of persons with physical dependencies by giving them greater choice and control over personal care and other in-home services and providers" (Kodner, 2003)
Service User	Consumer Client Recipient Participant Beneficiary	Person who accesses funding or services to meet their daily living needs.
Service provider	Agency Organisation Independent provider (in CDC model- Grossman et al., 2007) Support provider	"provider engaged to deliver care or supports" (Deparment of Health and Ageing, 2012)
Shared decision-making		"An interactive process in which clients and practitioners collaborate to make healthcare decisions. It assumes that both members have important information to contribute .....practitioners have information regarding diagnosis, course of illness (....etc).... clients are the experts of their own values, treatment preferences and treatment goals" (Adams & Drake, 2006) "the practitioner becomes a consultant to the client, helping to provide information, to discuss options, to clarify values and preferences and to support the clients" autonomy" (Adams & Drake, 2006)
Social Role Valorisation	SRV	Aimed to redress the mechanisms that lead to social devaluation through the enhancement of social valued roles. "The enablement, establishment, enhancement, maintenance and/or defense of valued social roles for people particularly those at value risk – by using as much as possible culturally valued means" (Wolfensberger, 1998).
Support	Personal assistance Personal care services Service Care	"assistance provided to people with disabilities of any age who require help with routine activities of daily living (ADLs) and health maintenance activities" (Kim et al., 2006) "includes a range of human assistance provided to people with disabilities and chronic conditions. PCS typically involves hands-on assistance with activities of daily living such as eating, bathing, bladder and bowel requirements and dressing and may also include instrumental activities of daily living such as preparing meals, assisting with medications and shopping for groceries" (Adelman et al., 2012) "Central goal is to enable people with disabilities and chronic conditions to live independently in their homes and communities rather than in institutions such as nursing homes". (Grossman et al.,

TERM	ALTERNATIVE TERMS	DEFINITION
		2007)
Support Worker	Employee Aide Paid carer Personal Care Assistant Community Worker Care advisor Worker Personal assistant Attendants Home care provider Caregiver	"paid worker who delivers formal care and support" (Deparment of Health and Ageing, 2012)
Unpaid carers	Informal family carers Surrogate Advocate Representative	Carer, family member or friends who provide services or support for which they are not paid (Deparment of Health and Ageing, 2012) Individuals selected by consumers to help them to make decisions regarding their support or act on their behalf (Carlson et al., 2007)

Appendix B: Historical Context

Disability care can be traced to B.C where death and abandonment was the common response as noted by Socrates, "the offspring of the inferior or the better when they chance to be deformed, will be put away in some mysterious unknown place, as they should be" (Roberts, 1981). The first known hospital to care for the unwell was built in Damascus in 706AD. After this time and until recent times 'models of care' were usually developed within a religious context which responded in a variety of ways from segregation to cures through to exorcism (Clapton & Fitzgerald, 1997). The following time line (adapted from Roberts, 1981) outlines some key historical matters relating to 'models of care':

- **1100's:** King Henry II purchases land for Newgate Prison
- **1200's:** Leper Colonies appear
- **1300's:** "Mad houses" are developed with the most famous living on in language legacy today, Bethlehem or "Bedlam" Hospital (1377)
- **1400's:** "Ship of Fools" response appears where people travel in boats acting as side shows across European seas and canals, another example of language legacy.
- **1500's:** Elizabethan Poor Law Act (1598) where parish support was given to find work for the poor. This was a time when there was recognition, through the work of physician Girolama Cardano, that the deaf can reason.
- **1600's:** A time of the plague and London fires it was also a time when the first private "mad houses" appeared.
- **1700's:** During this time period in the United Kingdom the Vagrancy Act was introduced for the detention of "lunatics". Bedlam Hospital continues to operate and the Madhouse Act was introduced in response to the appalling practices occurring in privatised "mad houses".
- **1800's:** The raising social consciousness in the community around the appalling treatment of vulnerable people is best exemplified at the *Pauper Asylum for Children* where two hundred children die of cholera creating an public outrage at the loss of life and the "farming" of children (Hallahan, 2006).

At this point in time we can turn to Australia and consider our historical responses to the more vulnerable members of the community. Obviously Australia has been greatly influenced by worldwide movements. Throughout the 1800's across the whole of Australia a number of large

"lunatic asylums" were built, one of the largest being Ararat Asylum (1865—1993) housing some 2000 people at its peak. In Queensland what is now referred to as "The Park" began in 1865 as Woogaroo Lunatic Asylum ("List of Australian mental asylums,"). Challinor Centre, opened in 1878, and is a Queensland example of a large scale institution (1000 children in the 1970)'s which was eventually closed (deinstitutionalisation commenced in 1994) by relocating people into a range of supported dispersed and cluster accommodation options (Young, 2006).

The twentieth century proved to be a time of significant change in terms of how people with disabilities were served in Australia and across the world. Models of care by now had moved from a religious to a medical to a rights based approach (see Clapton & Fitzgerald, 1997). Ultimately large scale institutional settings were closed or scaled down and the *community or independent living movement* emerged in the 1970's (Gloag, 1985) and took a firm hold by the end of the century. Less and less people remained living in congregated segregated care settings and resided in the community in a range of supported accommodation models (at home, group homes, small scale residential, cluster homes, residential campuses, village communities etc) (Young, 2006). Some key milestones over this century and beyond include (adapted from "Life to Live: The history of people with disabilities in Australia - 100 years,"):

- **1901:** Alice Betterridge was born, who became the first deaf/blind person to receive an education.
- **1950's**: the first sheltered workshops for children with disabilities appeared
- **1960**: Normalisation and Social Role Valorisation theories were articulated and applied across the world, where disability is recognised as a social construct
- **1975**: United Nations Declaration on rights of Disabled Persons
- **1970's:** Electric wheel chairs became available in Australia
- **1981**: International Year of Disabled Persons
- **1986**: Introduction of the Queensland Disability Services Act
- **1992**: Introduction of the Federal Disability Discrimination Act
- **2006**: COAG (Council of Australian Governments) decision to jointly fund the YPIRAC (Young People In Residential Aged Care) initiative to prevent early entry to; or move younger people out of residential aged care
- **2011**: Decision made by the Australian federal government to honour a National Disability Insurance Scheme (NDIS)
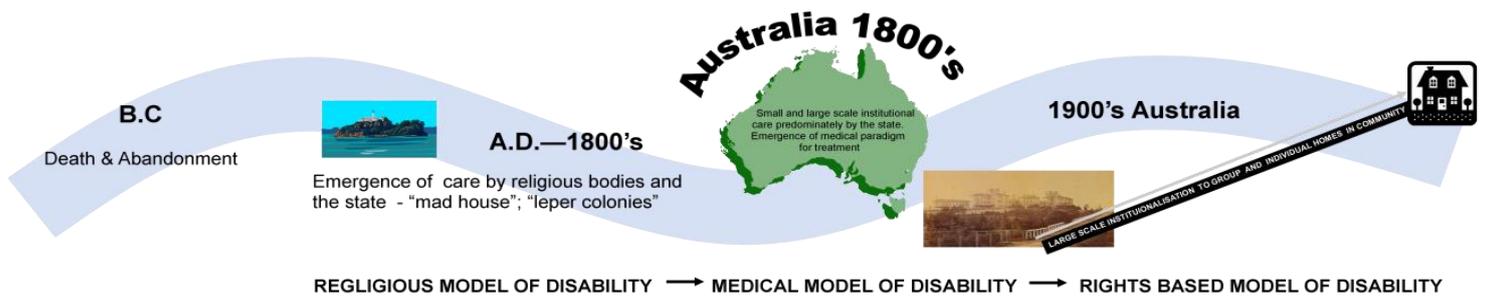
FIGURE 4 HISTORICAL SNAP SHOT

Appendix B References:

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