Support Needs Assessment for Individuals with Intellectual Disabilities: An Investigation of the Nature of the Support Needs Construct and Disability Factors that Impact on Support Needs.

Julia A. Harries

B.Sc (Hons)

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DEDICATION

To Richard

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Declaration

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Julia Harries and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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Abstract

Individualised needs based approaches are increasingly being utilised to fund disability support services. Frequently, standardised assessments such as adaptive behaviour scales and, more recently, measures of support needs are used for determining level of need. The aim of this thesis is to understand the relationship between adaptive behaviours and support needs and to investigate factors that impact functional capacity and need for supports for individuals with an intellectual disability.

Although a conceptually attractive approach to assessment, concern exists regarding the adequacy of the theoretical framework for guiding the development of support needs instruments. Though possessing theoretical similarities, adaptive behaviour and support needs scales are considered to measure different, albeit related constructs, prompting investigation into the nature of the relationship and the structure of the support needs construct. Accordingly, in Study 1 the Supports Intensity Scale (SIS), the Adaptive Behaviour Scale–Residential and Community (ABS-RC:2), and the Inventory for Client and Agency Planning (ICAP) were used to examine this relationship ($N = 80$). Dimensionality of the SIS (Section 1) was examined in reference to the three areas of conceptual, social, and practical skills, considered as comprising the adaptive behaviour construct. Factor analysis offered support for measurement of a common underlying construct. When considered in terms of the three adaptive behaviour skill areas, the support needs construct related predominantly to conceptual skills.

Unlike adaptive behaviour scales, little is reported about the properties of support needs measures or factors that impact on an individual's need for supports. Study 2 examined factors likely to influence adaptive behaviours and need for supports; in particular, the presence of coexisting disabilities. Using a measure of adaptive behaviour (i.e., ICAP) and

two support needs scales (i.e., SIS and the Service Need Assessment Profile, SNAP), the extent to which adaptive and challenging behaviours and support needs (including medical) were impacted by the number and severity of disabilities was examined (N = 83). Results showed adaptive behaviours and support needs (including medical) were meaningfully related to the number and severity of disabilities present, whereas this was not so for challenging behaviours. Profiles for challenging behaviour measures did not support a linear association with number and severity of additional disabilities, raising the possibility that the profiles were influenced more by the nature of the additional disabilities present.

Study 3 investigated the impact of the nature of the additional disabilities present on adaptive and challenging behaviours, support and medical needs using the same instruments utilised in Study 2. Each scale discriminated skills and needs associated with the presence of additional physical and speech disabilities. The support needs subscales of SNAP and SIS were more sensitive to the needs of individuals with coexisting neurological and sensory disabilities. SNAP was the only instrument to identify unique needs associated with the presence of a psychiatric disability but SIS was the only instrument to discriminate needs associated with the presence of a vision disability. Underlying this finding may be the importance of the person-environment interaction intrinsic to contemporary models of disability and support approach to assessment.

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SECTION A: Contemporary Disability Services: Funding Models and Costs of Service Provision

Chapter 1: Contemporary Funding Models

1.1 Project Background

The Disability Research Unit in the School of Psychology at the University of Adelaide has been involved in a collaborative research project with the Office for Disability and Client Services (ODACS) of the South Australian Department for Families and Communities (DFC). The aim of this research is the development of a model for understanding and determining the support needs of individuals with different types, levels and combinations of disabilities; although, the focus of this thesis is the support needs of individuals with a primary intellectual disability. The wider research project has addressed the assessment of support needs for people with disabilities receiving support services from service providers funded by ODACS, for the purpose of providing a rational basis for allocating resource funds. The intention was that such a system of funding supports would address shortcomings of traditional approaches to funding support services for people with disabilities. It was hoped thereby to produce noteworthy benefits for the key stakeholders of disability services, who include individuals with disabilities and their families/caregivers, disability service providers and funding bodies.

1.2 Service Funding Models in Australia

1.2.1 Government to Service Provider Funding Model

Thus far the arrangement under which disability service providers have been funded by the government in Australia has largely involved a traditional *government to service provider model*, based principally on the numbers of people *(consumers)* receiving services from the service providers. The amount of funding provided to support consumers has generally been established using approximate measures of needs, based on broad

categorisation of disability types and levels of disability served, with consideration in the formula for geographical location (i.e., rural vs. metropolitan location) (Baume & Kay, 1995; Yeatman, 1996). Additional to this recurrent annual block funding provided to service providers, extra funds have been made available over time to some service providers when the organisations have been faced with impending financial crises, changing occupational or safety standards or requirements, or for other special needs or projects. While intended originally to be available for use in exceptional circumstances, many of these *"one-off"* or *"bail out"* grants became a "*de facto*" method for increasing recurrent funding levels (Baume & Kay, 1995, p. 98). This approach to funding of disability support service, with its broad, imprecise determination of need and crisis management approach, has been widely criticised. It is reported to have resulted in funding imbalances across states, regions, service providers and individuals throughout Australia (Baume & Kay, 1995; Lindsay, 1996; Yeatman, 1996).

Overseas, comparable funding approaches have been criticised as leading to similar funding inequities (Fortune et al., 2005). Within the United States, congregate facilities have been funded on historical expenditure rates, negotiations with service providers, rate schedules and service operating costs, with little scrutiny of the characteristics and needs of service users beyond general consideration of service eligibility criteria (Fortune et al., 2005; Stancliffe & Lakin, 2005a). Similarly, regional inequities and difficulties allocating funds and resources on a "fair" basis have been identified in the United Kingdom (Emerson, 1999; Forsyth & Winterbottom, 2002).

1.2.2 Government to Service Provider Funding Models: Stakeholder Concerns Providing the Impetus for Reform

Although seemingly a simple approach to allocating funds, this traditional government to service provider funding approach has been shown to have a number of shortcomings and its continuance presents noteworthy concerns and challenges for all stakeholders in the disability sector and for the achievement of sector reform.

1.2.2.1 Funding Body Concerns

Sector reforms, including reforms of funding and service delivery approaches, have been a major focus for the government for several decades. Issues driving the reform of the disability sector have included:

1. *Increased demand for services*

Contributing to this increased demand for services have been changes in population demographics, a situation that is not unique to Australia. Underlying these demographic changes are advances in medical technology, which have resulted in reduced mortality rates and increased life expectancy for some people with early onset disabilities. These advancements have contributed to an increase in the numbers of people requiring services and have meant that those currently in receipt of services are also experiencing increased longevity (Emerson, 1999). However, associated with this increased longevity are age related declines in functional capacity, a consequence of which is the need for greater levels of support (AIHW, 2002c).

Furthermore, increased demand from ageing caregivers who are no longer able to support their family members with disabilities has placed further strain on the resources of disability support systems. Families who originally opted to provide "care in the family" (Cocks & Stehlick, 1996, p. 17) instead of placing their child in an institutional setting are now ageing; and are looking to disability services to provide ongoing care and support for their family members when they no longer have the capacity to care for them (AIHW, 2002c).

2. *Changed service delivery standards*

Consumer expectations of enhanced quality of service delivery, in accordance with legislative and philosophical advancements, have placed further pressure for reform of the disability sector. Early influences that have been prominent in instigating these changes were the civil and human rights movements and the emergence of the principle of normalisation.

This principle of normalisation, first developed in Scandinavia and then in the United States in the 1960s, became influential in Australia during the 1970s (Ashman, 1989; Cocks & Stehlick, 1996). Proponents of the normalisation principle advocated that people with disabilities should have a pattern of life and living conditions as close to, or the same as, those of society in general, and opportunities to fulfil socially valued roles (Ashman, 1989). In particular, the focus of the normalisation movement was the desegregation of living, schooling and work environments and enabling inclusion in mainstream services for people with disabilities.

The enactment of the Commonwealth Disability Services Act in 1986 provided the legislative basis for funding service provision in Australia in line with these philosophical changes. Accompanying this Act were a set of *Principles* (which outlined the fundamental rights of people with a disability) and *Objectives* for services to meet, in order to recognise the rights of service users. Fundamental changes accompanying the Commonwealth Disability Services Act included the downsizing of residential institutions and employment/activity services, disentangling the *whole of life* control of service providers over people with disabilities, and replacing medical models of support services with community based and integrated support models (Cocks & Stehlick, 1996; Lindsay, 1996).

In addition to the Commonwealth Disability Services Act (1986), several key policy and legislative initiatives have served to guide these changes, including the Commonwealth, State and Territory Disability Agreement (previously called the Commonwealth/State Disability Agreement), the Disability Discrimination Act (1992), and the Commonwealth Disability Strategy (1994). Underlying these initiatives have been the social justice principles of equal citizenship rights, equity and fairness of resource distribution, fair access to resources and services, and community participation and inclusion (DHS, 2003a).

In accordance with the Commonwealth State and Territory Disability Agreement (CSTDA) 2002-2007, ODACS has the responsibility for funding and administering a large range of specialist disability services including:

- *Accommodation support:* Includes services directed at enabling people with disabilities to remain in their existing accommodation or to move to more appropriate accommodation options. These services include accommodation (group homes, hostels and institutions) and support services (attendant care, in home support, and personal care).
- *Community support:* Includes services that assist people with disabilities to live and participate in the community, including case management, counselling, early childhood intervention services, therapy services, and regional resource and support teams.
- *Community access:* Includes services designed to help people with disabilities use and develop social independence skills such as day programs (other than employment), recreation and holiday programs.
- *Respite services:* Involves programs designed to provide a short term and time limited break for families and carers of people with disabilities and includes own-home respite, centre based respite and host family respite. (AIHW, 2002b)

Service providers funded to deliver these services vary considerably in size, geographic location, disability profiles served (frequently related to historical origins of the service provider), and models of service delivery. Some operate in desegregated and deinstitutionalised settings having achieved the prescribed (and preferred) service types outlined in the Commonwealth Disability Services Act (1986). Others have continued to operate as larger institutional, segregated facilities with care practices reminiscent of an earlier era. State/Territory governments run some services while non-government organisations run others.

A challenge when funding such a range of service types and diversity of service providers, is establishing a method for allocating funds in a manner that reflects the wide-ranging needs of the consumers utilising these services. Moreover, the government is challenged to ensure efficient and effective expenditure of public money by linking fund allocation to the achievement of desirable outcomes for service consumers. However, attempts to implement such *performance funding approaches* for disability services have not been straightforward. Essential to this funding approach is the capacity to ensure the adequacy of the monetary *inputs* and to obtain meaningful measures of the service *outputs*. Concern has been expressed that levels of input have not been satisfactory for all service providers, especially when considering the recognised funding inequities that exist between service providers. Additionally, the absence of any adequate benchmarking or rational process for establishing the support need levels of service consumers makes the process of ensuring adequacy of inputs problematic, limiting the effectiveness of this funding approach (Baume & Kay, 1995; Yeatman, 1996).

1.2.2.2 Disability Service Provider Concerns

Service provider concerns regarding the current state of funding of the disability sector relate to the issue of equity of fund allocation across services, the absence of a rational process for distributing funds, and concerns regarding the adequacy of present levels of disability funding to meet the needs of current and potential consumers of disability services, particularly in view of the increased demand for services mentioned previously (AIHW, 2002c; Baume & Kay, 1995; Lindsay, 1996; Ohlin, 1999; Yeatman, 1996). The traditional block funding method used for many decades to fund service providers, with its inexact need identification, lobbying and special case “pleading”, has resulted in a situation wherein service providers are competing with each other for their portion of the limited disability budget. This situation of service providers competing for limited resources, lobbying or

advocating for one disability group or service over others, has left disability service providers in a situation in which funding is considered to be at risk; and susceptible to pressure applied to political parties for additional support. The impact of such competition does little to engender an integrated and cooperative disability sector (Yeatman, 1996).

Further challenging service providers within the disability sector is an expectation that service delivery will be in line with contemporary principles of inclusive and person centred practices as prescribed under the Commonwealth Disability Services Act (1986). Moreover, this must be accomplished with levels of funding that were established using historical, institutional models of service delivery. A consequence of the discrepancy that exists between contemporary government policy requirements for operating services and the historical funding practices (with associated funding imbalances) is a continued reliance on welfare or charity money for large proportions of the disability sector (Yeatman, 1996). Yet such reliance also poses problems. Vulnerability of welfare or charity money, due to the capricious nature of donors and numbers of organisations competing for the charity dollar, requires substantial resources to be allocated to the fundraising efforts by disability service providers. A further downside of the need to undertake charity fundraising is that it serves to portray people with disabilities as needy or objects of pity, thereby requiring charitable support, which fosters societal attitudes towards people with disabilities as dependent and powerless (Turnbull, 1998).

1.2.2.3 Consumer Concerns

Equity is a major issue of concern for consumers of disability services. One such equity issue involves equity of support levels. Under current procedures, the level of support received by an individual does not necessarily relate to level of need but instead to the level of funding received by the service provider to support the individual. In the present circumstances, it is possible that two individuals with similar levels of need, but who are

supported by different service providers, could be receiving quite different levels of support funding. An additional but related concern is that of portability of funding. An individual receiving an adequate amount of funding allocated towards their support has no guarantee of receiving the same quantity of support funding should they need, or desire, a change of support service providers because funds are linked to the service provider and not the person dependent on them (Yeatman, 1996).

A further equity issue concerns access. A funding approach that funds service providers based on historical service models and levels of funding, rather than on specific needs of service consumers, provides little incentive for service providers to offer access to services to those individuals with complex high needs, due to fear of inadequate reimbursement for the provision of services. Likewise, the crisis-driven approach that has evolved in the disability sector has meant that individuals with low or moderate needs are not considered a priority and may also miss out on access to services. A corollary of this crisis approach is that the focus of service delivery is on the provision of supports required for *survival* or *maintenance*, rather than addressing both preventative programs for those with more mild to moderate disability levels and the provision of services that focus on quality of life issues and greater levels of participation in community life (Yeatman, 1996).

Underlying these support and access equity issues is a problem inherent to this traditional government to service provider based model of funding services, that is, responsibility for decision making and control of services. Various authors have expressed concern that, with this model for funding, responsibility for decisions regarding consumer access to services, as well as decisions regarding the nature, range, and quality of service provided, rests with the service providers, not the consumer (Dowson & Salisbury, 1999; Fortune et al., 2005; Lord & Hutchinson, 2003; Murphy, 1994). Understandably this situation is cause for concern for persons with disabilities and their families and is inconsistent with

contemporary philosophies that emphasise self-determination and the social justice principles that guide the operation of government services of equal citizenship rights, equity and fairness of resource distribution, fair access to resources and services, and community participation and inclusion for people with disabilities.

1.2.3 Individualised Funding Model

An alternative approach to funding disability supports is an *individualised funding* or *personalised approach*. With this model the allocation of funding is based on individual need; and funding commitments are made with the consumer, or person with a disability, rather than with service providers. The intention of this type of funding approach is to enable persons with a disability to exercise more control over the services they receive and the choice of preferred service provider. The goal of this type of funding approach is the enhancement of opportunities for self-determination and empowerment of the individual (AIHW, 2002c; Dowson & Salisbury, 1999; Laragy, 2002; Murphy, 1994).

Individualised models of funding supports were first developed in the 1970s. Driven by parent and consumer groups, this funding concept arose in two separate areas around the same time. One such program was established by a group of people with physical disabilities in Berkeley, California. Gaining control of funds previously provided by the government to support agencies, the group assumed responsibility for the employment and direction of their own personal assistants. Despite the burden of these additional administrative and employment responsibilities, many people took up this model of funding personal support services because of the added control and independence they gained over their own lives. Interest in this Independent Living Movement launched advocacy efforts for similar personal assistant services for people with physical disabilities throughout the western world (Dowson & Salisbury, 1999; Laragy, 2002).

In Canada, during the mid 1970s, another program was being established, which also focused on the provision of personalised supports. A group of parents, called the *Woodlands Parent Group*, all of whom had children living in the Woodlands Institution in British Columbia, advocated for an alternative model of care to the institutional care their children were receiving. They lobbied for, and established, community based alternatives for their family members, which were personalised to, and funded according to, the unique needs of the individual (Dowson & Salisbury, 1999, 2002; Laragy, 2002; Smith, 2003). The establishment of this program served as an impetus for other such initiatives world wide (Dowson & Salisbury, 2002).

Dowson and Salisbury (2002) have described individualised funding as having two fundamental characteristics. Firstly, the amount of funding provided is determined according to the specific and unique needs of the individual; secondly, the individual (and their personal network or support team) determine the manner in which the allocated funds are spent. There are several ways in which individualised models of funding may operate. For example, funds may be paid directly to the consumer for purchase of the services required, as is the case with the Direct Payments scheme used in the United Kingdom (Stainton & Boyce, 2004); the funds may be paid to a brokerage agency or fiscal intermediary to be allocated on behalf of the consumer; or funding bodies may contract a service provider to provide services, which have been identified as necessary for supporting the individual with a disability (Annison, Jenkinson, Sparrow, & Bethune, 1996; Dowson & Salisbury, 1999; Murphy, 1994).

Although this individualised model of funding is not used widely in Australia at present, its use is increasing in line with current government policies that encourage enhanced opportunities for integration, choice and self-determination (Annison et al., 1996). From a national perspective, around 17% of disability service users are reported to be in receipt of individualised funding from the government (AIHW, 2005). Service users aged between 15

and 24 years were the group most likely to receive these individualised funding packages (Ibid). Within South Australian, only 12% of the disability budget is reported to be delivered by means of an individualised funding method using a service brokerage approach (Caudrey, 2003). From an international perspective, while there has been an expansion of individual funding opportunities, relatively small numbers of people are reported to be in receipt of individualised funding (Bach, 2000; Lord & Hutchinson, 2003).

In a recent review of individualised funding (called Individual Budgeting) in Developmental Disabilities Program agencies in the United States, Moseley, Gettings and Cooper (2003) found that, while the use of individual budgets was a relatively new phenomenon for a number of the states surveyed, the use of this funding strategy was increasing. They reported that individual budgets were available in 32 of the 43 states (75%) that responded to their survey; however, extent of availability within the states varied considerably. Only seven (16%) of the responding states reported that these individual budgets were available to all service users; eight states (19%) indicated that individual budgets were available in many areas but not state-wide; and seventeen (40%) reported that they were available in some areas of the state or only in selected programs.

Individualised funding is available for people with disabilities within the United Kingdom in the form of Direct Payments. These payments, first implemented in 1997, are available for people assessed as requiring community care services in accordance with the Community Care (Direct Payment) Act, 1996 (Spandler & Vick, 2005). Payments can be used to employ a personal assistant, although other aids and services can also be purchased (Williams et al., 2003), but they can not be used for long term residential care (Stainton & Boyce, 2004). As in the United States, in the United Kingdom the allocation of these payments has been reported to vary across local authorities (Pearson, 2004). Additionally, variations have also been reported across different disability groups (Ridley & Jones, 2003;

Spandler & Vick, 2005; Williams et al., 2003), with greater use of payments for people with physical and sensory impairments than for individuals with intellectual disabilities and mental health service users (Pearson, 2004; Ridley & Jones, 2003; Spandler & Vick, 2006). Concerns have been raised that this imbalance relates to the requirement for the Direct Payment recipient to be able to manage the payments and, where required, the employer and administrative responsibilities (Ridley & Jones, 2003; Spandler & Vick, 2005, 2006; Williams et al., 2003).

The anticipated benefits of individualised funding methods are widely reported in the literature (AIHW, 2002c; Dowson & Salisbury, 1999; Laragy, 2002; Lord & Hutchinson, 2003; Moseley, Gettings, & Cooper, 2005; Torjman, 1996, 2000). Apart from the potential for obtaining equity with respect to resource allocation, the other reported benefits for the individuals with disabilities include:

- *Individualisation* - funding arrangements are tailored to meet the needs of the individual with a disability at that stage of their life and according to his/her unique circumstances.
- *Flexibility* – because funding is determined according to the needs of the individual, they are therefore able to be adapted as the needs of the individual change.
- *Portability* – because funding is associated with the individual and not with a service provider, the individual is able to change service arrangements and purchase supports from an alternative service provider.
- *Empowering* – consistent with the principles of self-determination and autonomy, individualised funding approaches enable individuals with a disability (and their support teams or networks) to choose the nature and provider of their disability related supports.
- *Accountability* – individualised approaches are considered to enhance the quality and manner in which services are provided because the service providers ultimately are

accountable to the consumer to whom they provide support. Fund recipients are accountable to funding bodies for the effective and responsible management of funds.

- *Inclusive* – because individuals are able to choose service providers, where possible they would be able to purchase support services from generic or community based facilities, rather than being restricted to obtaining services from formal services or traditional disability service providers.
- *Responsive* – individualised funding proponents consider that such a funding method serves to enhance the availability of supports for people with disabilities through the principles of supply and demand.

1.2.4 Factors Impacting on the Implementation of Individualised Funding Models

As already noted, there is wide agreement regarding the possible benefits of the individualised funding approach. Nonetheless, despite these advantages there are several potential problems or issues for all stakeholders, including the funding bodies, disability service providers, and service consumers, that may impact on the success of individualised funding methods.

1.2.4.1 Funding Body Perspectives

An individualised approach to funding services is substantially more complex and challenging for funding bodies than is the block grant system of the government to service provider models. Dowson and Salisbury (1999) consider that such a funding approach would require a more "sophisticated accounting system" (p. 5), in which support budgets are developed for large numbers of individuals, rather than a smaller number of service providers, while maintaining expenditure within the departmental budget limitations. An example of a funding body approach involving development of personalised budgets is the DOORS individual budget model used by the Developmental Disabilities Division in Wyoming, USA (Fortune et al., 2005). The DOORS model is used to establish an Individual Budget Amount

(IBA) for each individual receiving services and for determining the costs of providing supports for those on waiting lists for services. This model generates IBAs based on indicators of individual need and represents an individual's share of the available funds according to their assessed level of need. The model was developed by examining the mathematical relationship between actual costs and those factors that were considered to affect the cost of supporting different individuals. To develop the model, stepwise multiple regression methods, using previous reimbursement rates as the dependent variable, were used to identify the extent to which individual indicators of need explain differences in costs for different individuals. The model provides a means by which an existing disability budget can be fairly and equitably allocated across all support recipients.

However, a limitation of this model relates to the use of historical cost data. The model used previous reimbursement rates that had evolved overtime through a process of setting "rate schedules, overall cost caps and ad-hoc negotiation" (Fortune et al., 2005, p. 244) between the government and service providers. Consequently, as in the Australian system, funding disparities arose across the state and between individuals. An additional problem associated with the use of existing cost data was that of perpetuating funding inadequacies, such as inadequate staff wages, through the process of reallocating resources to obtain equity while constrained by existing historically established budgets (Fortune et al., 2005). The challenge for funding bodies is to be able to establish the true cost of providing support services for each person (Dowson & Salisbury, 1999), independent of the bias present in historical funding data.

Fundamental to the capacity to develop individual budgets such as the DOORS model is the capacity to identify the needs of individuals adequately and to allocate appropriate support funds to meet those needs. Important considerations in this process of identifying needs are the aspirations and preferences for support services of the individual. One

complexity associated with this process is the potential difference between the types of supports the individual may wish to have funded and the types of supports that the funding body may be prepared to approve and fund (Dowson & Salisbury, 1999; Forbes, 2000). The difficulty of discriminating “needs” from “wants” and of establishing criteria for supports considered appropriate to fund is yet a further challenge facing funding bodies in an individualised funding approach.

An associated dilemma for the funding bodies is the monitoring of individual budgets. Being accountable for the expenditure of public money, the funding body is required to ensure responsible use of individual budgets, without being too intrusive in the lives of people with disabilities. Also of concern to funding bodies will be the risk that needs, or the extent of disability, will be overstated by providers in order to receive increased levels of funding. A study conducted in Australia reported finding changes in assessed levels of need associated with the use of the assessment information for the purpose of service funding, with higher levels of need reported on the funding assessments than on assessments completed for research purposes (Guscia, Harries, Kirby, & Nettelbeck, 2006). Campbell et al. (2005) reported that, within the United States, funding bodies that have employed funding methods based on the characteristics or needs of consumers have experienced a movement of ratings to generate higher payments. Government funding bodies will be required to employ methods to reduce the risk of such “gaming” (Dyson, Duckett, & Allen, 2000, p. 642) or “rater bias” (Guscia et al., p. 156). Examples of approaches include, the use of independent assessors, using more than one assessor when gathering disability and need data, monitoring of data obtained from providers by funding personnel (including examining longitudinal trends), and the use of objective and auditable measures of need (Campbell et al., 2005; Dyson, Duckett et al., 2000; Fortune et al., 2005; Kirby, 2006; Schalock & Keith, 1986; Severance & Campbell, 2008).

Additionally, the role of the government in monitoring is considered to extend beyond these issues of integrity of the disability/need data. The premise underlying individualised funding approaches is that the disability sector would be able to operate like all market economy models, with consumers free to purchase services from any provider they consider appropriate, and to change providers if they are unhappy with the type of service provided. However, there is some thought that government regulation should continue, with safeguards to ensure that individuals receive quality services from accredited providers and that unprincipled providers do not enter the marketplace, thereby protecting the person with a disability from exploitation (Butterworth, 2002; Dowson & Salisbury, 1999; Kastner & Walsh, 2008; Laragy, 2002).

1.2.4.2 Disability Service Provider Perspectives

The crucial issue with respect to individualised funding approaches for disability service providers is that of viability (AIHW, 2002c; Butterworth, 2002; Dowson & Salisbury, 1999; Forbes, 2000; Laragy, 2002). Of particular concern is fund portability. This portability would enable dissatisfied consumers to leave a service provider and purchase support services elsewhere. However, this may serve to destabilise services and undermine the economic viability of the service. Although consumer satisfaction is of obvious importance, concern exists that fund portability may limit the capacity of the service provider to support other consumers adequately and may necessitate staff redundancies, which, in turn, may impact on staff morale. Such cut backs would inevitably adversely affect service flexibility to enable providers to deal with crisis situations (Dowson & Salisbury, 1999; Forbes, 2000).

Concerns regarding labour issues extend beyond these issues of resourcing support services. Under an individualised funding arrangement, consumers would be in a position to purchase supports or employ staff from a range of sources, not only from disability service providers. This capacity of consumers to employ care workers on an individual basis has led

to concerns being raised regarding possible adverse impacts on wage levels, working conditions, job security, career progression and training for care workers (Bleasdale, 2000; Dowson & Salisbury, 1999; Forbes, 2000; Laragy, 2002; Salisbury, 1997).

Transition to an individualised funding approach presents a number of challenges to service providers. Previously in the position to determine the nature, range and quality of services provided, under an individualised funding system service providers may be required to operate from a position where they are not only subject to the requirements of government policy but also required to respond to the individual requirements of their service consumers (Dowson & Salisbury, 1999). Dowson and Salisbury have suggested that the response from service providers to this type of restructuring of the disability sector will be mixed. Some service providers will respond favourably to the challenge, while others will find it a difficult process because of the costs, risks and uncertainty associated with changing a service.

1.2.4.3 Consumer Perspectives

Of all stakeholders, the consumers stand to benefit the most from the introduction of an individualised funding approach. Potential benefits include gains in self-determination, autonomy and enhanced dignity (Head & Conroy, 2005; Stancliffe & Lakin, 2005b). However, the system is not without potential problems or issues for consumers that require consideration.

1. *Equity of resource distribution and access*

Equity of resource allocation is a desired outcome for individualised funding approaches; however, attaining it is not as straightforward as it may seem (Maher, 2003). Dowson and Salisbury (1999) have suggested that true equity for all consumers will be difficult, if not impossible, to achieve and that inevitably demand for funds will exceed availability. The reality of fiscal budgetary constraints will mean governments will need to

make adjustments to individualised funding approaches (e.g., setting funding caps) to ensure there are no budgetary blow-outs.

The Wyoming DOORS model described previously involves an attempt to divide the existing fiscal budget equitably, to establish Individual Budget Amounts (IBA) for each person. Using this approach, individuals with greater needs receive higher levels of funding than individuals with fewer needs, but no representation is made that this amount will be an ideal level of funding (Fortune et al., 2005). The use of such models, which are designed to produce equity within the constraints of available funds, will undoubtedly limit the capacity to ensure the needs of all consumers are adequately addressed to each individual's level of satisfaction. Kastner and Walsh (2008) have described this type of approach to establishing individual budgets as "sharing the risk among all persons equally" (p. 240).

Additionally, with the DOORS model any changes to the overall available budget, the model used, or "mix" of consumers receiving services can potentially result in changes to the level of funding available for each person. Although the adjustments to IBAs are reported to be small, it does mean some people will receive more funding than previously, whereas others may receive less (Campbell et al., 2005; Fortune et al., 2005). The objective of the DOORs model of individualised funding is to achieve equity of resource distribution; however, a limitation of this type of model is the potential for the reduction in funding for some consumers, even though funding received previously may not have been ideal or sufficient to meet the individual's needs.

Such individualised approaches to funding do provide a means by which a more equitable approach to resource distribution can be obtained. However, individualised funding is not a solution to all the problems present in the disability sector and particularly to the under funding widely reported to exist in the disability sector (Dowson & Salisbury, 2002). For individuals with disabilities the consequence of sector under-funding include: restrictions

on the choice of support options that can be purchased, particularly for individuals with high or complex support needs associated with more severe levels of disability (Bach, 2000; Forbes, 2000; Maher, 2003; Perri, 2003); inadequate funding packages or highly restrictive funding caps, with some consumers finding it necessary to commit personal funds towards co-payments to subsidise service delivery or reduce hours of care received (Spall, McDonald, & Zetlin, 2005); limited new service development or innovation due to a lack of financial incentive for existing service providers to undertake such ventures or for new providers to enter the marketplace (Maher, 2003; Spall et al., 2005); and limitations on the numbers of people offered individualised funding packages (Maher, 2003).

2. Needs identification

Programs offering individualised funding approaches are not always successful at achieving the desired goal of fairness of resource distribution (Forbes, 2000; Maher, 2003; Perri, 2003; Spall et al., 2005). The challenge of developing methods for ensuring fairness and equity faces all programs offering individualised funding packages (Lord & Hutchinson, 2003). Models of individualised funding that aim to achieve equity, such as DOORS, are frequently guided by data derived from standardised assessments of level of disability or functional capacity. A concern for the consumers is the capacity of these assessment instruments to identify level of functioning and corresponding need levels reliably and accurately (Ridley & Jones, 2003).

Fortune et al. (2005) describe the DOORS model as a “best fit” (p. 254) model, which provides an accurate measure of resource requirements for the majority of consumers. Nonetheless, it is acknowledged that the model does over- and under-estimate the support requirements of some individuals. These individuals are described as “outliers”. Outliers are people who possess unique characteristics not well covered by the model, and, to date, these characteristics have included the presence of intensive medical needs, complex behavioural

needs, mental health issues, or needs that are changing (Fortune et al., 2005). Funding bodies employing best fit models to achieve equity of fund allocation should ensure appropriate mechanisms exist to review and appropriately modify the packages allocated to individuals with such high or complex needs or with needs that are changing.

Not all individualised funding programs use a *data driven* approach as with the DOORS model. Other programs develop individual budgets using qualitative or *developmental methods* involving a process of consultation with the individual and their caregivers in a person centred planning process (Moseley et al., 2005). In this planning process the individual's needs, preferences, and existing supports are considered in order to establish the individual's service and support requirements, the appropriateness of any requests, possible sources of support (including *informal* or unpaid sources of support) and costs. With these developmental approaches for establishing individual budgets, funding bodies need to take steps to ensure consistency and standardisation of the process, in order to guarantee equity across all applicants, as well as ensuring that financial expenditure is maintained within budget parameters so that the financial stability of the sector is maintained (Moseley et al., 2005).

Such individual funding methods with this personalised developmental approach to budget establishment eliminate the problem encountered in best fit models in which outliers are allocated inadequate funds due to unique characteristics. Nonetheless, this method is not without limitations. One criticism of this approach is the capacity of funding bodies to ensure equity across all claimants. Moseley et al. (2005) reported that states using this approach in the United States attempted to maintain equity across claimants through the use of standard forms, processes and decision making criteria; but acknowledged that variability in budgeting practices existed across state offices, counties and provider agencies.

Variability in individual budgets associated with different policy approaches or operational procedures, including different funding formulae, have also been reported in the United Kingdom (Evans, 2000; Perri, 2003) and in Australia (Forbes, 2000; Maher, 2003; Spall et al., 2005). Inequities in fund allocations, considered to result from budgeting processes that lacked transparency, or in which the "squeaky wheel" and most vocal received supports, have been considered as leading to a funding process that was competitive rather than needs based (Maher, 2003). This situation reflects criticism of current block funding models in which inequities exist between services and between individuals, leading to a suggestion that equity of fund allocation may be enhanced by basing payment on level of disability rather than on needs based assessment processes (Maher, 2003).

The process of determining an individual budget is by no means straightforward, with both the data driven models and developmental approaches demonstrating shortcomings. Moseley et al. (2005), in their comprehensive review of budgeting processes, considered that no one approach or model is believed to be a best practice approach for determining individual support needs for the purpose of establishing individual budgets. Neither approach solves the dilemma of balancing the funding of a person's expressed support requirements while maintaining financial expenditure within budget limits.

3. Fund administration

It is apparent that individual budgeting approaches, while having the potential to deliver a number of benefits to individuals with disabilities, are not without their own set of challenges for consumers and their support networks. Negotiating with funding bodies about payment levels is only one aspect of fund management that may fall to the consumer and their family under individualised funding approaches. Additional management responsibilities could include the development of expenditure plans, the employment of support staff, and the

maintenance of appropriate records (e.g., employee related and expenditure records) (Dowson & Salisbury, 1999).

Some individuals may consider these management and accountability responsibilities complex and onerous or may require support to undertake these tasks (Evans, 2000). Funding bodies can alleviate this problem by having a range of different approaches to the management of individualised funding packages. Individuals comfortable with the management responsibilities may have the funds paid directly to them for purchase of the services required. Alternately, for those not wanting or unable to take on the management responsibilities, the funds may be paid to a *fiscal intermediary agency* to be allocated on behalf of the consumer, or funding bodies may contract a service provider or brokerage agency to provide and/or arrange particular services that have been identified as necessary for supporting the individual with a disability (Annison et al., 1996; Dowson & Salisbury, 1999; Murphy, 1994). Important to the concept of individualised funding is flexibility; consequently, funding bodies may need to offer a variety of program options to address the needs of consumers in this area.

4. Consumer Choice

Fundamental to individualised funding is the notion that funds are associated with an individual and that the consumer directs the choice of service provider (Dowson & Salisbury, 1999; Moseley et al., 2005). It has been suggested that this arrangement, in which the consumer moves from being a passive service recipient to having purchasing authority, is likely to induce the development of new services and will provide greater choice of service providers (Dowson & Salisbury, 1999; Spall et al., 2005; Torjman, 2000). However, Torjman (2000) has cautioned that new service developments are unlikely to occur at a rapid rate in the short term or even in substantial quantities, citing the need for specialist staff training or environmental modifications as potential inhibitors to fast paced service development. Failure

to generate new services or improved efficiency of existing service delivery was reported by Spall et al. (2005), in a qualitative review of the experiences of individually funded consumers in Australia. Additionally, various authors have reported that consumers find themselves purchasing supports or services, not on the basis of the supports being their desired option, but because they are the only suitable options available, albeit not perfect (Maher, 2003; O'Brien, 2001; Spall et al., 2005).

1.3 Service Funding Models Summary

Although there are notable problems associated with the traditional government to service provider approach to funding disability services, the literature also reveals a number of potential challenging issues for funding bodies, service providers and individual service consumers associated with the use of an individualised approach to funding of supports. These issues have led various authors to warn that such a funding approach requires cautious and incremental implementation and that it may not prove to be the most suitable funding approach for all service types or individuals (AIHW, 2002c; Dowson & Salisbury, 1999; Laragy, 2002; Torjman, 2000). In view of these cautions, it seems that funding bodies may need to employ a flexible approach to the funding of services and individuals, offering different funding methodologies across service types or according to individual preferences.

Widely considered as fundamental to the achievement of equity and the reform of funding approaches is the concept of linking resource allocation to individual support needs or functional limitations. However, while encouraging this approach, Forbes (2000) has warned that funding formulae based on such indicators may underestimate the real cost of service provision, and particularly of infrastructure and indirect costs. Embarking on changes to funding methods requires an understanding of the extent to which the cost of service provision is driven by the needs of service users and the extent to which other factors are critical in costing.

Chapter 2: Costs and the Relationship to Needs and Outcomes

2.1 Cost of Service Provision

A review of the literature from Australia and overseas reveals that there are many variables that have been investigated to determine their impact on the costs of service provision and outcomes, when providing support services to individuals with disabilities. Much of this research has involved costs associated with residential settings for individuals with intellectual or developmental disabilities; however, while this is the case it does serve to demonstrate the complexity involved in separating out cost components in order to establish the relationship between needs and costs. Further, the relevance of this research is apparent when considering the expenditure patterns within Australia for Commonwealth State and Territory Disability Agreement (CSTDA) services. According to the Australian Institute of Health and Welfare (AIHW, 2005), people recorded as having an intellectual or developmental disability as their primary disability constitute 51% of total CSTDA service users, with funding for accommodation support constituting the largest proportion of CSTDA funding (accounting for half of total expenditure). Similar levels of expenditure (54%) have been reported from the United Kingdom for accommodation/residential support (Felce et al., 2008).

The cost variables that have been investigated include both service and resident characteristics. Service characteristics that have been explored with regard to their impact on service costs and outcomes include, (i) facility characteristics, such as geographic location (e.g., urban vs. rural), type of ownership/management (e.g., government vs. non government), facility size, model of service delivery, the number of basic and additional services provided, and years of operation; (ii) the working practices or service processes, including the social climate established, procedures for staff training and supervision, and procedures for resident assessment, planning, training and support; and (iii) staffing issues, including numbers of

qualified staff, staffing ratios, staff wages, staff turnover and staff unionisation. (Campbell & Heal, 1995; Emerson, 1999; Emerson et al., 2005; Felce, Jones, Lowe, & Perry, 2003; Felce, Lowe, Beecham, & Hallam, 2000; Felce et al., 1998; Fortune et al., 2005; Hallam et al., 2002; Hatton, Emerson, Robertson, Henderson, & Cooper, 1995; Lakin, Hewitt, Larson, & Stancliffe, 2005; Rhoades & Altman, 2001; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lakin, 1998; Walsh, Kastner, & Green, 2003)

Resident characteristics that have been investigated include (i) demographic characteristics such as age, gender, and ethnicity; (ii) residential history including age when entering residential care, time spent at residential placement, and the number and type of previous residential placements; and (iii) the functional skills of the individual including the severity of intellectual disability, the presence of other impairments, physical and mental health needs, adaptive behaviours and support needs, and the presence of challenging behaviours. (Campbell & Heal, 1995; Emerson, 1999; Emerson et al., 2005; Felce et al., 2003; Felce et al., 2000; Felce et al., 1998; Fortune et al., 2005; Hallam et al., 2002; Hatton et al., 1995; Lakin et al., 2005; Rhoades & Altman, 2001; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lakin, 1998; Walsh et al., 2003)

Findings from such studies have demonstrated a number of associations with service and resident characteristics and the impact on service costs and outcomes, although authors have cautioned against generalising results due to study limitations. Limitations reported have included small sample sizes (Emerson, 1999; Felce et al., 2003; Felce et al., 2000; Hatton et al., 1995); samples restricted or not representative of the broader population of service recipients (for example, with respect to need levels, secondary disabilities, medical conditions) (Stancliffe & Keane, 2000; Stancliffe & Lakin, 1998); participants and/or agencies not randomly selected (Emerson, 1999; Emerson et al., 2005; Hallam et al., 2002); possible subject reactivity to observer presence (Hatton et al., 1995); evaluations conducted at

only one time point, making it difficult to determine whether the cause of observed outcomes was due to the service model or possibly the developmental phase of the individual (Hallam et al., 2002; Hatton et al., 1995); no correction or controlling for disability severity or case-mix differences in a heterogeneous population of service recipients (Walsh et al., 2003); difficulties accurately apportioning costs per resident on a usage basis, or disentangling complex funding strategies (Felce et al., 2008; Stancliffe & Keane, 2000; Walsh et al., 2003); problems generalising results to other countries due to uniqueness of national funding policies (Felce et al., 2003); the age of a national data set not adequately reflecting more recent service developments (Rhoades & Altman, 2001); and use of cost data in analyses that have been established using historical approaches to fund allocation (Fortune et al., 2005).

Despite these limitations, what is apparent from the literature is that a number of complex factors impact on costs and result in cost variations, not only between service providers in a service system but also within service providers (Felce, 1994; Walsh et al., 2003). In their review of the literature associated with costs in residential settings, Walsh et al. reported that costs vary between similar types of services on the basis of factors such as geography (rural vs. metropolitan location), staffing factors (numbers of professional staff, staff ratios, staff wages and benefits), type of ownership/management (government vs. non government facilities), or consumer characteristics including functioning level. They cite a study by Hatton et al. (1995) as an example of within service variations, in which cost differences were obtained for different service models even when located in the same setting (i.e., comparing two services located within an institutional setting and two located in community settings). Additionally, Walsh et al. reported that costs can vary within services over time; for instance, when residents from an institution are placed in community based alternatives. Such deinstitutionalisation programs have frequently involved the movement of the more capable residents from the institution, leaving the institution to support those

individuals with more severe and complex disabilities or with more challenging behaviours who require greater staff input, with associated higher costs per resident (Rhoades & Altman, 2001; Walsh et al., 2003).

2.1.1 Relationship between Costs and Needs: Research Findings

An association between service costs and level of need of service consumers appears logical, in that it does not seem unreasonable to expect that individuals with more severe or more complex disabilities would possess fewer daily living skills or have more complex behavioural or medical problems and so would be expected to receive greater levels of staff support and consequently higher per person costs (Felce et al., 1998; Stancliffe & Lakin, 2005a). Available literature, however, indicates that the exact nature of the relationship between needs (or resident characteristics) and costs (or expenditures) is not yet clear, with varied results reported.

2.1.1.1 Research from Australia

In a study conducted in Australia of outcomes and costs of community living, Stancliffe and Keane (2000) used a matched group comparison of residents (N = 54) with low to moderate support needs living in group homes and semi-independently. Groups were matched according to adaptive and challenging behaviour scores from the Inventory of Agency and Client Planning (ICAP). When considering costs, they found per person expenditure for direct support staff costs to be substantially greater for group home participants and, given that the groups had been matched for support needs, the large cost differences between the two models appeared not to be needs based.

Further analysis of these data by Stancliffe (2005), using a full sample of 90 people rather than the matched samples, allowed more detailed analysis to be undertaken to examine factors associated with service costs. Using backward multiple regression techniques the variables associated with service recipient's characteristics and service types were examined

to determine which were related to the cost of service provision. In this analysis, it was found that factors such as higher assessed support needs (and adaptive and challenging behaviour scores when entered separately), possessing a chronic health problem, and location (rural vs. metropolitan) were not significantly associated with direct support staff costs. However, two resident characteristics (older age and having a formal psychiatric diagnosis) and four service characteristics (living in a group home, smaller residence size, residence size by type interaction, and government operated service) were found to be associated with higher direct support staff costs, accounting for 80% of the variance associated with these costs. The results indicated that per person staff costs were only minimally needs based and that the major factors associated with these costs were service model characteristics.

Stancliffe reported significantly fewer semi-independent residents (9%) had psychiatric diagnoses compared to group home residents (27%). Likewise, fewer semi-independent residents (4%) had chronic health problems than did the group home residents (24%). Nonetheless, Stancliffe reported that the relative homogeneity of the sample may have impacted on the results obtained. This study examined residents with low to moderate support needs with few or no challenging behaviours; a more diverse sample may have produced different associations between costs and personal characteristics (Stancliffe, 2005).

2.1.1.2 Research from the United Kingdom

Studies from the United Kingdom have reported variable results with regard to the relationship between service costs and indicators of level of need (or resident characteristics). Reporting on the results of three studies, Emerson (1999) concluded that “the relationship between indicators of need and resource allocation are, at best, weak” (p. 313). In the first reported study, no relationship was found between level of ability and costs of care packages or staff to resident ratios for residential services for 42 people with severe intellectual and dual sensory disabilities. A second study, involving 44 people with intellectual disabilities

with severe challenging behaviours living in community houses, similarly found no relationship. Furthermore, no relationship was found between either care package costs or staff to resident ratios and severity of challenging behaviours. However, a moderate association between adaptive behaviour and costs of care packages and staff to resident ratios was reported in the third study involving 271 people with intellectual disabilities living in small community based houses for eight people or less. A weak association was found between challenging behaviour and total costs, with challenging behaviour explaining 3% of the cost variance.

Contrary to this, a study by Felce et al. (2003) involving 51 group homes in Wales found higher costs were associated with higher levels of challenging behaviour. Scores on the Aberrant Behaviour Checklist were found to explain 26% of the variance associated with the cost of actual staff hours (outside of day service hours). An earlier study conducted by Felce et al. (1998) in Wales involving people with severe intellectual disability and severe challenging behaviours living in either community houses or traditional (institutional) service settings did not support this finding. Instead, they reported finding no relationship between severity of disability and costs when considering data from both of the residential services types. However, when service types were considered separately, a moderate association between severity of disability and accommodation costs was found for the community houses. Further analysis of these data using multivariate regression analysis revealed large differences in the cost of community based and traditional settings that were not related to resident ability, even though costs were found to be greater in each service model for residents with lower ability (Felce et al., 2000).

Multivariate analysis was used to examine the association between costs and level of need for residents (N = 500) in a variety of residential settings within the United Kingdom including village communities, dispersed housing schemes and residential campuses

(Emerson et al., 2005; Hallam et al., 2002). Higher costs were found to be associated with lower resident ability and the presence of more severe challenging behaviours (17% of the variation in costs) with gender and age explaining a further 2% of the variation. Higher costs were found to be associated with male service users, although gender differences were not explained by differences in levels of ability or challenging behaviours. Higher costs were also associated with younger service recipients, a finding that differs from Stancliffe's (2005) Australian study, which reported higher costs for older service users. The higher costs for younger service users were considered to be related to younger service users generally receiving more expensive accommodation options and day placements. Analysis of the data for a subgroup of this study group living in a dispersed housing scheme (n = 281) found similar, although slightly stronger, results for the association between costs and level of need, with adaptive behaviour explaining 22% of cost variations and gender and age accounting for 3% of the variance (Emerson et al., 2005).

Felce and Emerson (2005) reported that resident characteristics (e.g., age, adaptive and challenging behaviours) accounted for between one quarter and two fifths of variations in costs for residential facilities. Furthermore, Felce et al. (2008) suggested that the predominance of the fully staffed group homes as a residential model for deinstitutionalisation in the United Kingdom has served to lessen any association between indicators of costs (e.g., staff ratios) and indicators of resident level of need (i.e., resident characteristics) across residential facilities. They considered, therefore, that the capacity does exist to augment the relationship between level of support funding and level of need.

2.1.1.3 Research from the United States

The research examining the relationship between resident characteristics or need and service costs in the United States has similarly produced varied results (Felce et al., 2003; Stancliffe & Lakin, 1998; Stancliffe & Lakin, 2005a). Some studies have found a strong

association, including a study conducted in South Dakota (N = 1295) by Campbell and Heal (1995). While they found local community (10.6%) and provider characteristics (11.7%) to be contributors to cost variation, they reported that as much as 63.2% of cost variation was associated with individual resident characteristics. However, other studies have shown no significant association.

One such study, in which no significant association was found, was conducted by Stancliffe and Lakin (1998) in Minnesota. Using backward regression, resident and service characteristics were examined as predictor variables for expenditure for 116 adults with severe or profound intellectual disabilities. The results indicated that resident characteristics (adaptive and challenging behaviour) were not significant predictors of expenditures (including staffing, residential or total costs), whereas several service characteristics including state versus private ownership, institutional or community placement, and staff ratios were found to be significant. Stancliffe and Lakin suggested that the difference between these findings and those of Campbell and Heal (1995), while consistent with findings from a study undertaken in Michigan by Ashbaugh and Nerney (1990), may be related to having investigated a restricted group of service users, whereas Campbell and Heal were able to include the full range of service users in South Dakota.

A large study conducted by Rhoades and Altman (2001) attempted to gain a national perspective on the relationship between residential expenditures and resident and service characteristics. In this study, results similar to those reported by Campbell and Heal (1995) were found with service characteristics, local community characteristics and resident characteristics all influencing the cost of service provision. With reference to resident characteristics, they found higher costs to be significantly associated with level of intellectual disability, with people with severe and profound levels of functioning having higher daily expenditures than persons with borderline to moderate levels of functioning. Additionally,

they found higher daily expenditures associated with greater need for assistance with daily living tasks, and for younger residents (under 22 years of age). Moreover, they found that expenditure for individuals with ambulation problems, additional developmental disabilities, or behaviour problems did not differ significantly from those without such problems, although the additional support for these factors might have been expected to result in extra costs for these individuals. Another unexpected finding of the study involved an association between higher costs and non-White residents, which Rhoades and Altman were unable to explain, although they suggested a possible interaction with facility characteristics such as regional location and size of facility for non-White residents. Other "non-resident" factors found to be associated with higher expenditures included type of ownership/management (i.e., government facilities were found to be more expensive), larger size facilities, and geographic location. Their results also demonstrated other interactions between resident characteristics and facility characteristics. For example, they reported an association between level of intellectual disability and facility size, revealing that care was more expensive in larger facilities (16 or more beds) for individuals with borderline, mild, moderate, or severe levels of intellectual disability. However, facility size was not found to be a factor for individuals with profound levels of intellectual disability, with minimal increases in expenses likely to be associated with moves to smaller facilities. This research illustrates the complexity underlying variations in service provision costs and difficulty involved in establishing a "one size fits all" funding formula.

Recent research from the United States has examined variations in service costs in an attempt to develop and/or review models for generating individual funding formulas. An example of this research is the examination by Lakin, Hewitt, Larson, and Stancliffe (2005) of the Minnesota Waiver Allocation Structure (WAS). Introduced in 1996, the WAS is a four level system for allocating funds for new people entering the state's Home and Community

Based Services (HCBS) program. The waiver allocation is determined based on assessed personal characteristics (i.e., functional, physical, medical and behavioural needs) with the funds paid to the appropriate county rather than to the individual. There is no requirement that the budgeted amount actually be spent on that individual but, rather, the funds are managed by the county as a combined budget of resources. A review conducted of expenditures using hierarchical regression found a weak relationship between the four funding levels and actual expenditure for individual recipients, with the WAS levels accounting for only 3.1% of the variance. However, as WAS funding levels had only been applied to recipients who had entered the program since 1996, there were a number of people within the sample who were in receipt of a previous base rate level of funding. A reanalysis of a sub sample excluding these individuals found that the WAS levels accounted for 8.4% of the variance in expenditures. This indicated that while the state funding policy was needs based, the payment system to the counties had not translated to need based allocations to individuals. Lakin et al. also found when considering the whole study group that additional personal characteristics (e.g., adaptive and challenging behaviours, medical and mental health status), explained an additional 15.3% of variance in expenditure. This indicated that personal characteristics associated with having higher support needs (i.e., more severe intellectual disability, having fewer adaptive skills, the presence of more challenging behaviours, requiring specialised or intensive medical treatment, needing mental health services, or requiring physical therapy) were associated with higher expenditures. Other factors found to be influencing expenditures for the whole sample included number of days of service (9%), services received (32%), residential setting (4%), and county characteristics (2%). Lakin et al. concluded that, while expenditures were related to the needs of service recipients, expenditures were related to a number of factors beyond the individual's level of need.

Before the DOORS model was implemented in Wyoming, a payment system similar to the Minnesota WAS was utilised. This system involved five payment levels linked to the service needs of individuals based on scores obtained using the ICAP (Fortune et al., 2005). The decision to change the payment system arose due to concerns regarding the appropriateness of the five funding levels and the fairness of the system. Of particular concern with this system was the problem that small differences in ICAP scores could result in major adjustments to the level of funding provided to support recipients. Consequently, Wyoming moved from this funding level approach to using a system under which each person received an Individual Budget Amount (IBA). This model (DOORS) involved objectively assessing an individual's skills and behaviours, as well as consideration of types of support services received by the individual, in order to establish the budget amount. A comparison of the two funding approaches by Fortune et al. revealed that greater variance in expenditure amounts were explained using the DOORS model than the five tier system (increasing from 52% to 75%), with the proportion of variability associated with assessed individual characteristics rising from 37% to 47%. These results indicate that it is possible to improve the strength of the association between individual characteristics and expenditure by utilising a *continuous payment system* such as the DOORS model, compared to funding models involving the use of discrete funding levels.

Campbell et al. (2005) undertook a similar regression analysis to that used with the DOORS model using a larger data set (N = 7611) involving four Western US states (Nebraska, South Dakota, Montana and Wyoming). In this analysis, they found that 71% of variance associated with individual costs could be explained by the regression model. Variables contributing to this figure included residential and day programs received (32%); adaptive and maladaptive (challenging) behaviour scores (28%); other functional skills (communication, mobility, and health) and diagnostic information (5%); geographic measures

(4%); and other support services received and funding source (2%). Overall they found higher expenditures for individuals with more severe levels of disability (i.e., fewer adaptive behaviours and more severe challenging behaviours). Other personal characteristics that were found to be associated with higher costs included: having fewer communication skills, a diagnosis of brain damage, autism, or mental illness; need for assistance with mobility; need for medical care. With respect to age they found costs were less for older service recipients.

The cost studies reported thus far have generally used inferred measures of need (i.e., levels of need implied on deficits scores on adaptive behaviour and challenging behaviour measures and/or personal characteristics such as the presence of particular impairments or health conditions) to examine the relationship between costs and level of need. Two recent studies have used a scale called the Supports Intensity Scale (SIS; Thompson et al., 2004), which is an instrument that has been designed specifically to measure the intensity of an individual's support needs. In the first study Thompson et al. (2004) undertook a multiple regression analysis to examine variations in costs. They obtained a model that explained 68% of the variation associated with individual costs. Consistent with previous United States studies that utilised adaptive behaviour measures (Campbell et al., 2005; Fortune et al., 2005), they found 36% of the variation in costs was associated with personal characteristics as established using the SIS. In particular, this percentage comprised diagnosis of a psychiatric disorder (7%), the presence of exceptional medical and behavioural needs (12%), and support scores on 11 of the 49 items of the Support Need Scale (17%). Similar to the findings of Campbell et al., 32% of the variation in costs was explained by type of residential setting and day program (sheltered employment). A second SIS study by Severance (2007) involved comparing an adaptive behaviour scale (the ICAP) and the SIS to see whether one instrument predicted current expenditure rates better than the other; or whether using a combination of the two improved predicability for costs of residential and day support services. For each

service type, ICAP predicted slightly higher variance (25% for day services and 32% for residential services) than did the SIS (24% for day services and 28% for residential services), and combining the measures increased the variance predicted marginally (31% for day services and 36% for residential services). While methodological issues, particularly the use of historical expenditure patterns, impact on the results of these cost and need studies, these results further highlight the fact that, even when using an instrument that has been specifically designed to measure support needs, other factors (e.g., characteristics of the residence) remain important determinants of costs of service provision.

2.1.1.4 Relationship between Costs and Needs Summary

Research into the relationship between costs and needs from Australia, the United Kingdom, and the United States have revealed similar findings, although comparatively little published research exists from Australia. Reported associations between personal characteristics (or level of need) and variations in costs have ranged from no association through to strong associations. Additionally, these studies have established that variations in service costs are associated with more than the characteristics of the service user, with the various studies reviewed indicating the importance of other factors including facility and locality characteristics. It is important to note that many of the findings reported relate to the results of multiple regression procedures. While these findings point to factors that are associated with variations in costs, these factors may not necessarily be the cause of cost variations (Severance & Campbell, 2008).

Central to any discussion of cost of service provision is the importance of ensuring that allocated funds result in meaningful outcomes and good quality of life for service consumers. While the cost of service provision and effectiveness of expenditure are significant concerns for all stakeholders, additional costs may be justified if associated with quality outcomes for consumers. Consequently, funding bodies worldwide are faced with the

difficult balancing task of allocating funds in a manner that not only reflects the needs and aspirations of individual consumers but also of ensuring opportunities for achieving effective outcomes, while making prudent use of public dollars (Schalock & Keith, 1986).

2.1.2 Relationship between Costs and Outcomes

Central to individualised budget models is the idea that fund allocation, which is more closely associated with an individual's needs, allows greater opportunities for adequately addressing support requirements and achieving positive outcomes for individuals. However, research on the relationship between lifestyle outcomes and expenditures for individuals with disabilities has produced varied results, as with studies investigating the relationship between needs and expenditures, with some finding associations while other studies fail to demonstrate any relationship (Felce et al., 1998).

Outcomes addressed in the literature have included quality of life and quality of care indicators such as involvement in social activities and social relationships; levels of community integration and use of community facilities; participation in domestic activities; staff and resident interactions including support levels; choice and autonomy; health and safety issues; the presence of challenging behaviours; and levels of satisfaction. (Emerson, 1999; Emerson et al., 2001; Emerson et al., 2000; Felce, Lowe, & Jones, 2002a; Felce et al., 1998; Felce & Perry, 1995; Felce et al., 2003; Felce et al., 2008; Hatton et al., 1995; Lakin et al., 2005; Perry & Felce, 2003; Robertson et al., 2004; Stancliffe, 2005; Stancliffe & Keane, 2000; Stancliffe & Lakin, 1998).

Many studies have addressed the relationship between outcomes and expenditures through comparisons of outcomes for residents in traditional institutional facilities to those of residents in community based options. There is wide support internationally for improved outcomes in community settings, including greater involvement in community activities, more engagement in domestic tasks, increased levels of choice, enhanced social interactions and

family contact (Emerson & Hatton, 1996; Heller, Miller, & Hsieh, 2002; Kim, Larson, & Lakin, 2001; O'Brien, Thesing, Tuck, & Capie, 2001; Stancliffe & Lakin, 1998; Young & Ashman, 2004; Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). However, analyses of expenditures in the two environments have produced conflicting results. Within the United States, community based services are generally considered to be less expensive, whereas in the United Kingdom community services are by and large more expensive (Felce & Emerson, 2005; Stancliffe & Lakin, 2005a). Methodological difficulties associated with this research, including differences in the populations served and funding strategy complexities have been cited as possible reasons for the differences between study findings (Walsh et al., 2003), although there is growing acknowledgement that staff wages may be a significant cause of this discrepancy (Kastner & Walsh, 2008; Rhoades & Altman, 2001; Stancliffe & Lakin, 1998). Direct care staff in non-state run community services in the United States have been reported to receive lower wages and benefits than staff employed in state run institutions, a discrepancy that is not reported in the United Kingdom (Felce & Emerson, 2005; Lakin & Stancliffe, 2005; Larson, Lakin, & Hewitt, 2002). This finding complicates any analysis of the relationship between outcomes and expenditures in such service model comparisons, particularly in the United States.

Studies undertaken comparing the outcomes and expenditures between institutional and community based services in the United Kingdom, where staff wage differences are not considered to be a confounding factor (Felce & Emerson, 2005), have revealed an ambiguous relationship (Emerson et al., 2000; Felce et al., 1998). Hatton et al. (1995) studied the relationship between costs of different service models and outcomes. In this study, they compared the cost and quality of four different residential service models for individuals with intellectual and sensory disabilities. The service models examined varied in terms of their location (i.e., two located within an institutional setting and two located in community based

settings) and according to whether they were *specialised* (for sensory impairments) or *ordinary* service models. The study results indicated that institutional-based services were more costly, although lifestyle and service outcomes were superior in the specialised community-based group home model. Additionally though, while they found variation in quality between service models, they also reported considerable quality variation within service models.

Felce et al. (1998) also addressed the issue of quality and service expenditures or costs in a study comparing traditional and community based residential services. Contrary to the finding of Hatton et al. (1995), they found community based services to be more expensive than institutional services. However, as found by Hatton et al., they also found superior quality of life outcomes associated with the community based services, but concluded that the higher costs of these services "could not be related to benefit" (p. 390). Indeed, one of their findings was that outcomes were significantly and positively associated with resident ability, a finding that has been widely reported elsewhere in the literature (Campbell, Fortune, & Heinlein, 1998; Emerson, 1999; Felce et al., 2003; Felce et al., 2000; Felce et al., 2002a; Felce & Perry, 1995; Felce & Perry, 2004; Hatton, Emerson, Robertson, Henderson, & Cooper, 1996; Mansell, Beadle-Brown, MacDonald, & Ashman, 2003; Perry & Felce, 2003; Perry & Felce, 2005; Stancliffe & Lakin, 1998).

Emerson et al. (2005) examined this relationship by comparing outcomes and expenditures across different service models including residential campuses, village communities and dispersed housing schemes (including supported-living schemes). In these comparisons, they found costs to be higher for community based service models than for institutional types of services. Additionally, they reported inferior quality of care and quality of life outcomes associated with the institutional services offered at the residential campuses when compared to the dispersed housing schemes examined. Moreover, they reported that

these outcome differences were not related to the characteristics of support recipients but suggested that the additional costs associated with dispersed housing services may be reasonable, given the better outcome findings. While reporting a "modest positive association" (p. 169) between costs for the dispersed housing scheme and better outcomes, results of multivariate analyses indicated that service costs were not related to outcomes for support recipients. Nevertheless, in common with Hatton et al. (1995), *within* service differences in quality were found in the dispersed housing schemes, with larger group homes associated with poorer outcomes than smaller group homes or supported–living schemes, and different patterns of benefit were associated with smaller group homes and supported-living schemes.

Within the Australian context, Stancliffe and Keane (2000) examined the relationship between outcomes and service expenditures in a matched group comparison of residents living in community based group homes or living semi-independently. They found higher costs associated with group home service provision. When considering outcomes they generally found outcomes did not vary significantly between the two groups, although where differences were present, outcomes were better for the residents living semi-independently. In particular, these outcomes included more frequent independent use of community facilities, reduced social dissatisfaction, greater involvement in domestic tasks and more independent choice making. The results of this study indicated that higher expenditure was not associated with improved outcomes but, rather, was associated with service models.

The weak relationship that has been reported to exist between expenditures and outcomes suggests that other factors may be significant determinants of service quality. Research on other variables has addressed service characteristics including *service design*, such as facility size, age, architecture, location, and staff to resident ratios, and *service processes* such as the working methods and procedures adopted by staff. Underlying the

process of deinstitutionalisation has been the premise that improved outcomes for people with disabilities would result from moving people from congregate care services, which generally involve large non-homelike buildings segregated from the community, to smaller services with typical housing designs located within community settings. While deinstitutionalisation research has found evidence supporting this premise, to date the impact of individual variables on outcomes has been unclear and frequently the results of research have been confounded by other variables, such as different service models or resident ability (Emerson et al., 2001; Felce et al., 2008; Perry & Felce, 2005; Stancliffe, 1997).

Elements of service design that have received considerable attention include setting size and staff to resident ratios, while considerably less attention has been directed to variables such as home-likeness and degree of community integration (Perry & Felce, 2005). The association between setting size and costs has been addressed in terms of the "*diseconomies of reduced scale"* associated with the downsizing of institutional facilities, in which per person costs increase as facility numbers decrease due to the presence of fixed or semi-fixed facility operating costs that cannot be further reduced proportionately to resident numbers (Stancliffe, Lakin, Shea, Prouty, & Coucouvanis, 2005, p. 296). Research that has addressed the issue of economies of scale associated with larger facilities compared to smaller settings has produced equivocal results, indicating that the situation is complex. Additionally, findings may be confounded by factors such as facility ownership (i.e., state and non-state facilities), service types, and support need levels of residents (Felce & Emerson, 2005; Stancliffe & Lakin, 2005a). However, when considering cost variability within service models, the available literature indicates that economies of scale have little impact on costs of community based residential services, although higher per person costs can be expected in very small facilities in which the presence of 24 hour support staff is required (Felce & Emerson, 2005; Lakin & Stancliffe, 2005).

When considering the impact of setting size on outcomes, the available literature reports contradictory findings, although studies that have examined outcome differences associated with moves from large scale institutional facilities to smaller community based options have generally reported benefits associated with such transitions (Felce & Emerson, 2005). While some positive associations with smaller setting size have been reported, mixed results have also been regularly reported. For example, Perry and Felce (2005) examined outcomes associated with group homes. They concluded that, while smaller setting size was infrequently associated with better outcomes, when it was found to be influential, mixed outcome associations with smaller settings were evident. For instance, they found smaller settings to be associated with greater levels of choice while residents of larger settings participated in a greater range of activities. Outcomes that have been reported to be positively associated with smaller setting size have included: having a larger social network (Emerson et al., 2001); more participation and access to community activities (Emerson et al., 2001; Felce et al., 2000); greater resident autonomy (Felce et al., 2000); more involvement in domestic activities (Felce et al., 2000); and wider levels of choice (Robertson et al., 2004; Stancliffe, 1997; Tossebro, 1995). Outcomes that have been reported to be negatively associated with smaller setting size have included: fewer scheduled day activities (Emerson et al., 2001); greater risk of being exploited or likelihood of being subjected to acts of vandalism or abuse (Emerson et al., 2001; Emerson et al., 2005); and lower observed resident engagement in activities (Felce et al., 2002a). Although various studies have reported the benefits of smaller setting size that might be intuitively expected, it appears that quality (or the achievement of desired lifestyle outcomes) requires more than the placement of people in smaller residences considered to be typical of “ordinary” households (Heller, 2002; Jones et al., 1999).

Moves from institutional settings that were frequently characterised by low staff to resident ratios and low levels of resident engagement in activities (Jones et al., 1999), to

community based housing, were expected to give rise to staff to resident ratios more in keeping with the needs of residents and the achievement of enhanced resident outcomes (e.g., greater resident involvement in activities). Yet, studies on the impact of staffing levels or staff to resident ratios have produced varied results (Felce, Lowe, & Jones, 2002b; Perry & Felce, 2005). While positive outcomes have been linked to the presence of higher staff to resident ratios, for example, receipt of more attention from staff (Felce et al., 2003), other studies have found that staff to resident ratios are not important factors in determining outcomes (Felce, 1998; Hatton et al., 1996; Stancliffe & Lakin, 1998). Studies have reported unfavourable associations between higher staff to resident ratios and outcomes; for instance, higher ratios have been negatively associated with levels of empowerment or choice, use of community facilities, and participation in domestic activities (Felce et al., 2000; Felce et al., 2008; Robertson et al., 2004; Stancliffe, 1997). Further, Robertson et al. (2004) in a study examining the quality and costs of community based services for people with intellectual disabilities and severe challenging behaviours, found that despite high staff ratios (2.6 staff: 1 resident) in services that congregated people with challenging behaviours, residents spent the majority of time either disengaged (39%) or engaged in stereotyped behaviours (29%) while receiving staff contact for only 17% of the time. As with other elements of service design considered thus far, mixed findings have also been reported with regard to staff to resident ratios. For example, Felce et al. (2002a, 2002b) found higher staff to resident ratios to be associated with greater involvement in community activities for residents. They also reported that higher ratios were associated with lower levels of resident involvement in household duties and less time spent by each staff member with residents, instead finding that higher staffing levels resulted in greater staff to staff interaction.

Various studies have demonstrated that levels of staff interaction do not necessarily match the needs of residents (Felce & Perry, 1995; Felce & Perry, 2004; Jones et al., 1999). A

study by Felce and Perry (1995) examined the relationship between staff level of interaction and resident ability. They expected that residents with higher needs would receive more support from staff; however, this was not found. Instead, they reported that residents with similar levels of need received widely varied levels of staff contact. They found that staff caring for people with the highest support needs (i.e., having greater disability levels or more challenging behaviours) spent less time interacting with residents than staff working with more capable residents. While adequate staff levels are important, Felce and Emerson (2005) reported that the research suggests there are "diminishing marginal returns from adding staff to a given situation and that staff deployment may be more important than staff numbers per se" (p. 57). Increasingly research into service quality has suggested that characteristics of the service, beyond service design features, may be important mediating factors in determining service quality and the achievement of lifestyle outcomes (Jones et al., 1999; Perry, Lowe, Felce, & Jones, 2000; Robertson et al., 2004).

Aspects of service processes, such as working methods and procedures (including staff deployment methods) have been investigated with respect to their importance in determining service quality. These procedures include: (i) the training, supervision and support of staff, (ii) the allocation of support staff to residents, and (iii) planning of activities. As with service design considered previously, studies regarding service processes have also produced diverse results. Emerson (1999) has reported that the use of "more sophisticated internal planning procedures for the training, supervision and support of staff" (p. 315) has been found to be associated with better outcomes, including greater choice, increased social and community integration, and a reduction in risk. However, Perry and Felce (2005) reported that outcomes were not predicted by the extent to which systems were in place to plan and support the activity of residents and for the training and supervision of staff. Felce et al. (2002a) reported the presence of a higher percentage of qualified staff to be associated with less resident

involvement in domestic tasks. Jones et al. (1999) examined the impact on outcomes of providing staff with training in Active Support; a training procedure that includes activity and support planning and training on the provision of effective support, with a focus on resident involvement in decision making and individualisation of preferences. They found that it was possible to promote greater resident engagement in activities at home, more efficient use of staff time, and enhanced levels of staff assistance to residents through the use of Active Support. In addition, they reported a reversal of the pattern in which more able residents received greater attention and assistance following the implementation of Active Support training, with these improved outcomes occurring without increasing staff numbers.

2.1.3 Relationship between Funding Models and Outcomes

The finding of improved outcomes associated with more individualised models of support raises the question of whether improved outcomes are associated with the use of individualised models of funding in contrast to traditional funding models. Limited research is available on the benefits and nature of changes associated with individualised funding and support models (Lakin & Stancliffe, 2005), largely as a result of the newness of this funding model.

Stancliffe and Lakin (2005b) examined the relationship between funding models and outcomes using cross sectional data collected for a self-determination demonstration project in Michigan. In this analysis they considered one outcome, freedom from staff control, and compared results for individuals receiving an individual budget with those not receiving individualised funding. They reported only a modest link between the availability of individual budgets and freedom from staff control, indicating that availability of an individualised budget alone was not sufficient to ensure increased choice and control. They concluded that a longitudinal analysis examining a broader range of outcomes would provide

a more comprehensive analysis of the benefits and impacts of individual budget availability on outcomes.

A subsequent longitudinal analysis of this project by Head and Conroy (2005) examined the impact of the self-determination and individualised funding process on outcomes and costs for 70 people. In this project, a person centred planning process was used to identify support requirements and establish a support budget for the individual to manage. Quality of life data and cost information were collected before (1998) and after (2001) the implementation of the self-determination and individualised funding process and results compared. Head and Conroy reported a consistent pattern of positive benefits that they considered to be associated with the self-determination process. In particular, gains over time were apparent on measures of power, quality of life, self-reports of satisfaction with life, and involvement in socially integrated community activities. Additionally, while costs for some individuals increased, overall they found an inflation adjusted cost reduction of 16%. Although no predetermined budget caps were used in the budgeting process, case managers were encouraged to develop new budgets using a target amount that was less than that of the cost of historical service provision for each individual. Head and Conroy speculated that contributors to the cost reductions achieved included the use of targets as well as creative, non traditional approaches to accessing support services. While no control or comparison group was used in this analysis, to enable a comparison of individual versus traditional funding approaches, the results do support the benefits of self-determination and individualised budgets and suggest that improvements in quality of life are not necessarily associated with increased costs.

2.1.4 Costs and the Relationship to Needs and Outcomes Summary

Research into the cost of providing residential support services, and, in particular, research into the relationship between resident needs and service costs (or expenditures) has

revealed varied results ranging from no association through to strong associations. Contributing to the diverse findings are numerous methodological challenges and confounding factors that have complicated the understanding of this relationship. However, what does seem evident from the literature is that the relationship involves a complex interaction of characteristics associated with the resident, facility and locality. What is also apparent is that not all sources of cost variation have yet been identified, with some authors suggesting that there may be resident specific factors that impact on the cost of service provision, but which are not adequately measured by the various instruments used in the cost studies (Emerson et al., 2005; Felce et al., 2000; Hallam et al., 2002). The similarity of the findings associated with the use of deficit based, implied measures of need (i.e., adaptive behaviour scales), and the use of an instrument designed specifically to measure the intensity of support required in the cost studies, further emphasises the possibility that other important factors associated with the individual are yet to be identified.

Guscia, Eckberg, Harries and Kirby (2006) have suggested that one area not well assessed by instruments that are used within the disability sector is that of the environment and, in particular, the impact of the environmental factors on an individual's need for support. They have recommended more comprehensive assessment of the environment utilising the World Health Organisation's (WHO) International Classification of Functioning, Disability, and Health (ICF; WHO, 2001), and particularly, using the five environmental chapters (Products and Technology; Natural Environment and Human-Made Changes to the Environment; Support and Relationships; Attitudes; and Services, Systems and Policies) as a framework for identifying key impact factors. The likelihood that other factors, beyond those currently investigated, are impacting on need for support has implications for the development and/or revision of existing standardised instruments intended to be used for the purpose of establishing individual budgets.

Although the results of studies on cost of service provision have produced ambiguous results, various authors have warned that decisions regarding the types of service models to be funded should not be based on economic issues alone (Hallam et al., 2002; Stancliffe & Lakin, 2005a). When making decisions regarding the funding of services, consideration needs to be given to the achievement of positive lifestyle outcomes for service recipients. However, outcome research has also produced equivocal results. Studies into the relationship between service costs and the achievement of lifestyle outcomes for service recipients have also reported varied findings. Variability has been reported not only when examining the differences in outcomes and costs between different service types but also when comparing similar service types. Emerson (1999) reports the association between costs and the achievement of positive outcomes to be generally weak. Conversely, resident ability has been found in numerous studies to be significantly positively associated with outcomes. More recently, studies have investigated the association between outcomes and individualised approaches to service delivery and funding. Results of such studies support the outcome benefits of these individualised approaches, with there being some indication that such approaches are not necessarily more expensive than traditional funding and service planning approaches (Heller, 2002; Jones et al., 1999).

2.2 Funding Models and Costs of Service Provision: Summary and Implications

The challenges facing funding bodies both within Australia and overseas reflect those confronting other human service and health care sectors. Operating in a situation of fiscal constraint, these sectors are currently experiencing increased demands for services, due in part to changing population demographics and expectations from consumers of receiving higher quality service delivery in line with technological, philosophical and legislative advances. The reform process put in place to address the demands facing the disability service system has involved attempts to restructure service provision and prioritise resource allocation, while

attempting to maintain a focus on service quality, accountability and the prudent expenditure of public money.

Guiding these changes to disability legislation and service provision have been the principles of social justice, including the principles of equity and fairness. Of particular importance to the reform of disability service provision is the reform of funding practices, from traditional government to agency based funding models to individualised models of funding, in an attempt to achieve equity and fairness of resource distribution, and fair access to support services. Individualised funding approaches are recognised as a means for reducing inequities. While there are potential benefits associated with individualised funding methods, this approach can also have shortcomings. Continued viability of agencies has been highlighted as a significant concern associated with the introduction of individualised funding methods, with concern expressed that funding support services according to the needs of service users may not adequately cover the real cost of service provision, particularly indirect or infrastructure costs.

An approach to funding that has the needs of the service user as the key determinant of funding levels is in contrast to traditional funding methods, which have largely focused on the funding of service models, with only very general consideration of the needs of service users. Traditional funding methods, which have utilised imprecise measurements of need and a crisis management approach, have been criticised as resulting in inequities for individuals across the sector with respect to both access to services, quality of supports received, and outcomes obtained. These inequities potentially mean that some service users are under supported according to their level of need while others may be over supported. The weak or absent association reported in some studies in the literature between cost of service provision and both level of service recipient need and service outcomes (used as a measure of service quality) underscores these access and quality inequities.

Although a number of studies have reported this weak or absent association, this finding has not been universal. Others have reported varying levels of association, ranging from moderate to strong associations. Moreover, similar variability has been reported in studies investigating the association between cost of service provision and service quality. Variability in costs and quality are reported to exist not only between different service types but also within the same types of services. The analysis of these relationships is not straightforward, with studies challenged by methodological and confounding factors; however, as previously noted, what does seem apparent is that underlying these relationships is a complex interaction of characteristics associated with the resident, facility and locality.

While not yet universally used, individualised need based approaches for funding disability support services are increasingly being used both within Australia and internationally. Funding bodies employ different approaches for the establishment of individual budgets to fund disability support services. Some involve the use of objective assessment systems and are described as being data driven while others use a qualitative or developmental approach. Each approach is reported to have shortcomings and currently there is no one model that is considered to be a best practice approach for determining individual support needs for the purpose of establishing funding amounts, although increasingly data driven approaches are being used in an effort to ensure consistency, transparency, and equity.

Although only limited research thus far has addressed the outcome benefits associated with such individualised approaches to fund allocation, there is initial support for the benefits associated with the use of such approaches and, in particular, with regard to self-determination. Numerous authors have reported an association between positive consumer outcomes and level of ability (i.e., adaptive behaviour). A fundamental goal of disability service provision should be the achievement of quality outcomes for all service consumers. On the basis of the well documented association between adaptive behaviours and quality

outcomes for consumers, Stancliffe and Lakin (2005b) suggested that the development of an individual's adaptive behaviours is likely to have significant impact on their quality of life. They cite as an example, the provision of training in the area of communication skills, which could significantly enhance an individual's capacity to communicate with others regarding preferences when making choices. Such capacity is likely to have significant consequences in terms of their capacity for self-determination. The importance of focusing on training goals as a means of enhancing quality of life outcomes for individuals should therefore be an important consideration when establishing an individual's development plan (or person centred plan) and the associated personalised budget. As such, it is desirable that any need identification process encompass the identification of appropriate training needs and resources, in addition to identifying other types of supports an individual may require (Kirby et al., 2004).

2.2.1 Implications for Resource Allocation Strategies and Needs Assessment Process

The complexity of the situation associated with the funding of support services, as well as the need to ensure positive outcome benefits for recipients, highlights the need for further research into funding methodologies and methods for identifying needs. Lakin and Stancliffe (2005) state that the "further development, evaluation, and refinement of procedures to establish rational, reliable, and appropriate levels of funding for individuals needing support will be an important task for researchers, funders, and policy makers for the foreseeable future" (p. 329). This review of the literature has highlighted a number of important factors for consideration when establishing and using needs based resource allocation strategies. Additionally, it has highlighted a number of implications for the development and/or refinement of assessment instruments to be used for the purpose of identifying needs for the purpose of funding support provision.

2.2.1.1 Implications for Resource Allocation Strategies

In terms of the implications for the process of using individualised needs based methods for the allocation of support resources, the following issues have been identified as important in the literature reviewed.

1. *The assessment procedures used for determining funding levels need to be coherent with the assessment procedures used for allocating supports and developing support plans.*

Variability exists regarding the way individualised funds are allocated and managed. Some funding bodies pass the control of the funds directly to the individual and/or their support team. Others make allocations to regional or local government agencies to be managed on behalf of the individual. The method used for allocating funds can impact on the strength of the eventual association between needs and expenditure. This was particularly evident with the Minnesota Waiver Allocation Structure (WAS) reported by Lakin et al. (2005). This program was designed to provide a *needs based funding system*; however, the separation that existed between the needs identification for funding purposes (and placement into a waiver level) and need identification that existed at the program or support planning level, resulted in a system with only a weak association between waiver level (or identified level of need) and actual expenditure. This result highlights a research and development priority for ensuring consistency between the measures or procedures used to determine funding and the measures or procedures used for establishing each individual's program and support requirements.

2. *Resource allocation systems should include review mechanisms to ensure appropriate level of fund allocation to all recipients.*

As indicated in the review of the literature of individualised funding, there is variability across the disability sector regarding the methods used for allocating support funds. Some funding bodies utilise a continuous payment system (such as the Individual Budget Amounts generated by the DOORS model), whereas others have funding models

involving the use of discrete funding levels. Research reveals that a stronger association is obtained between individual characteristics (or level of need) and expenditure when continuous payment systems are used, compared to programs involving discrete funding level payment systems. Underlying this result is the variability in skills and needs that may be present in any one funding level and the fact that individuals with similar skill or need levels may potentially be placed in different funding levels if their assessment scores place them at the periphery of two funding levels. Small changes or differences in assessed skill or need levels are unlikely to result in large differences in level of funding received with continuous funding payment systems, whereas this may not be the case with funding approaches that utilise discrete funding levels. The practical challenge for researchers and funding bodies when using a discrete funding level approach is not only to develop reliable and valid measures to be used as a basis for establishing individualised needs based budgets, but also to ensure adequate mechanisms exist for reviewing those individuals whose assessment results place them at the periphery of a funding level. Such review mechanisms would help to reduce opportunities for funding inequities to arise, while ensuring the adequacy of support provision. These review procedures may include mechanisms such as complementary or additional supplementary assessments, which are utilised when an initial assessment produces a funding "cusp" result or capacity to collect critical qualitative information to enable funding bodies to determine an appropriate funding level.

3. *Resource allocation systems established for identifying and funding supports on the basis of need should include adequate mechanisms for identifying and reviewing outliers.*

Research has indicated that the process of establishing individual needs based budgets is anything but straightforward. Despite attempts to establish best fit models for the allocation of fiscal resources in a manner that is considered fair, rational and transparent, it is apparent that there are individuals not well accommodated in these models. These individuals, described as outliers, arise when using the best fit models, despite the fact that objective

measures of skills or needs are utilised within these models (Fortune et al., 2005). These individuals appear to possess unique characteristics not adequately assessed using existing measures for establishing support needs or well covered in existing individualised funding models. They serve to highlight the dilemma associated with establishing a one-size-fits-all formula. Consequently, resource allocation systems should include the capacity to use alternative or additional methods to refine the level of funding required for such individuals. However, care needs to be taken to ensure that such corrective mechanisms do not result in allowing or promoting "special pleading" by more powerful advocates that eventually restores existing inequities that are considered unfair. Information obtained regarding the particular unique characteristics of outliers could also be used to improve the comprehensiveness of the assessment system over time. These outliers highlight the complexity surrounding the assessment of support needs and reinforce the need for research to enhance understanding of the concept of support needs and factors that impact on need for support. This area of understanding the concept of support needs will be an area of investigation for this thesis.

4. Systems established to provide need based funding should include mechanisms for ensuring the integrity of the assessment information to avoid the possible overstating of needs.

Funding approaches that utilise needs based assessments as a basis for determining level of fund allocation are at risk of what has been described as gaming or rater bias. Higher support need ratings, or greater ratings of extent of disability, have been reported when assessments have been used to generate need based funding levels. Underlying these increased ratings of level of need or disabilities, are attempts to ensure adequate levels of funding for family members or clients, yet the use of such an approach places at risk attempts to achieve true equity in the funding of supports. Additionally, while disability budgets have been described as inadequate to meet current levels of need for service recipients in Australia (Yeatman, 1996), the potential over-estimating of needs to increase the amount of funding received may result in greater levels of unmet need across the disability sector and for those

on waiting lists, as the disability budget is further stretched. A consequence of this may be greater levels of competition and discontent between providers and individuals, a situation reminiscent of the historical government to service provider funding approaches. Funding bodies will need to employ various approaches in order to check assessment information and confirm need ratings provided. Suggestions offered in the literature for checking the integrity of the assessment data include the use of independent assessors, using more than one assessor when gathering disability and need data, monitoring of data obtained from providers by funding personnel (including examining longitudinal trends), and the use of objective and auditable measures of need.

2.2.1.2 Implications for Needs Assessments

In terms of the requirements for an assessment system to be used for an individualised needs based resource allocation approach, the following factors have been identified as important in the literature reviewed.

1. *Instruments used for the purpose of need identification must be sensitive to the needs of individuals with a range of different disability types, levels of severity and combinations of disabilities.*

The literature reviewed thus far has indicated the relevance of individual characteristics (e.g., level of adaptive behaviour, the presence of particular disabilities or health conditions) on support provision and associated costs. Consumers of disability services constitute a heterogeneous group of people who have various unique disability related needs associated with either their primary or coexisting disabilities. It is important when quantifying needs for the purpose of funding supports, to understand the impact of the nature and severity of an individual’s primary and coexisting disabilities on functional capacity and consequent need for support. This area will be further investigated in this thesis.

2. *Assessments designed or used to measure need for support must consider other personal factors or factors external to the person that may impact on level of support required.*

Findings in the literature have led various authors to suggest that there are factors associated with the individual that have not yet been adequately identified and that are likely to impact on the type and intensity of supports that an individual may require. It is likely that these factors are not well addressed by the assessment approaches investigated so far, which have largely been deficits based approaches and most frequently adaptive behaviour assessments. Possible factors may include ***personal factors*** that extend beyond the type and severity of the person's disability. Examples of personal factors include:

a. *Age or developmental life stage*: Although contradictory findings have been reported regarding the impact of age on cost of service provision, the literature has reported variations associated with support recipients from different age brackets (e.g., Campbell & Heal, 1995; Emerson, 1999; Rhoades & Altman, 2001; Stancliffe, 2005). It is possible that need for support (and associated costs of support provision) varies across different life or developmental stages, rather than support needs and costs remaining constant across an individual's life span (Stancliffe, 2005). For example, service recipients in the adolescent/early adulthood age bracket may need greater levels of support to be directed towards them as they make the transition from school to work or other day options. Additionally, older service recipients may require greater support and funding as they experience age related deterioration in skill levels associated with increased incidence of health/medical conditions.

b. *The presence of changing needs*: While the impact of changing needs has not been widely investigated in the literature reviewed, Fortune et al. (2005) identified individuals with changing needs as amongst outliers in the DOORs model used in Wyoming. In addition, there are a number of circumstances in which conditions associated with deteriorating functional capacity have been identified as being associated with higher costs and greater need for

support. In particular, the presence of health/medical conditions has been found to be associated with greater costs and needs in a number of studies (e.g., Campbell et al., 2005; Fortune et al., 2005; Lakin et al., 2005; Stancliffe, 2005; Thompson et al., 2004). The identification of such health/medical conditions in a need assessment system would facilitate proactive planning of supports, in view of the anticipated changes in health and functional status.

c. *The presence of a fluctuating condition*: A number of studies have identified the presence of mental health or psychiatric diagnoses as an influential factor associated with costs of support (Fortune et al., 2005; Stancliffe, 2005; Thompson et al., 2004). Associated with mental health conditions are fluctuations in symptoms and capacity to function independently, with these fluctuations often associated with issues such as medication compliance, age related changes or personal and/or environmental factors (Cortese, Malla, McLean, & Diaz, 1999; Huxley & Baldessarini, 2007). However, most assessment approaches utilise a "snapshot" approach assessing skills or level of need at the given point in time and are unlikely to take into account fluctuations in level of capacity associated with mental health problems or other fluctuating health conditions and the likely consequent changes in level of need. Funds allocated on the basis of such a snapshot assessment may be insufficient to address needs when fluctuations in capacity occur and result in need for greater levels of support.

d. *Cultural or religious background:* Little is reported in the literature reviewed in this chapter regarding the impact of cultural or religious background on costs or need for support. Rhoades and Altman (2001) reported an unexpected association with respect to expenditure differences for White and non-White residents of facilities in the United States; however, they speculated that this finding was related to an interaction with facility characteristics. Although little has been reported and further research is indicated, there is reason to suppose that

differences in costs and level of need may arise due to unique cultural or religious factors. This would certainly be the case in circumstances where the person also lived in a remote rural location (e.g., if the person was of an indigenous background living in a remote community). The capacity of a need assessment to identify these cultural or religious factors would therefore assist with the provision and costing of such resources and enhance quality of life outcomes for these individuals.

As well as personal factors associated with the individual, the literature also indicates that factors external to the person impact on the need for, and cost of, support provision. Various studies have reported the importance of service and locality characteristics. Such external or ***environmental factors*** could include a broad range of factors, from those that facilitate independent functioning (e.g., the availability of appropriate assistive technology and devices or the presence of a supportive network of family and friends), through to factors that impede functioning (e.g., lack of adequate specialised transport or diminished caregiver capacity due to ill health or ageing), or factors associated with operating policies for service providers (e.g., occupational health and safety regulations such as minimum number of staff required to be on duty for night support in residential settings, care-giver qualifications needed for administering medications or special treatments). As with personal factors identified above, the capacity of an assessment system to identify such issues would be a useful resource for directing and costing of supports with the aim of improving quality of life outcomes.

3. Assessments designed to measure need for support should focus on training needs as well as supports directed towards maintaining the person.

While it is important that individuals receive the supports they require to enable performance of daily living skills (e.g., eating, dressing, bathing, using the toilet) and instrumental tasks of daily living (e.g., shopping, cleaning, meal preparation, money

management), there are indications in the literature regarding the benefits of enhancing an individuals capacity in the area of adaptive behaviours. As mentioned previously, the close link that exists between resident ability and the achievement of quality outcomes has led Stancliffe and Lakin (2005b) to suggest that enhancing an individual's level of ability could have positive implications in terms of quality of life. The capacity of a support needs instrument to identify and direct the provision of training supports has the potential for improving outcomes for individuals, as well as having potential positive benefits for funding bodies and service providers, as the increased independence of some individuals may result in the freeing up of support resources, which can then be directed towards supporting others; however, it could also lead to fears that increased skills will lead to the withdrawing of funds, thus providing a disincentive to improve such skills.

4. The needs based assessment system should contribute to the measurement of outcomes.

The use of individualised needs based funding and assessment approaches has the potential to produce benefits for all stakeholders in the disability sector. For instance, it provides a means by which funding bodies can distribute funds equitably and rationally, a significant improvement for service providers and consumers. Furthermore, the use of a comprehensive needs assessment system provides a mechanism by which estimates of unmet need can be established for budget negotiation purposes. Most importantly, the needs assessment system should contribute towards the identification and measurement of consumer outcomes. The success of a needs based assessment system should be determined by the extent to which it leads to improvements in quality of life and opportunities for self-determination for consumers.

2.2.1.3 Implications for Research

The literature reviewed has revealed a number of important issues for consideration when utilising needs based and individualised systems for funding the provision of disability

supports. Some of these issues relate to the process involved in using such a needs based resource allocation strategy, while others relate to requirements of a needs based assessment system. The achievement of equity of fund distribution requires reliable and valid mechanisms for quantifying level of support needed. The development of new instruments or the refinement of existing instruments for determining level of need for people with disabilities requires an understanding of the construct of support needs, as well as the factors that are likely to impact on need for support, such as the presence of coexisting disabilities. These areas will be examined further for individuals with intellectual disabilities in this thesis.

SECTION B: Conceptualising Support Needs

Chapter 3: Needs Identification and Adaptive Behaviours

3.1 Needs Identification

Fundamental to the implementation of needs based funding is the capacity to identify adequately the support needs of individuals with disabilities. Recent research into needs based funding methods has highlighted the complexity involved in understanding and determining the needs of recipients of disability support services. Varied approaches for establishing individual support budgets are presently used both within Australia and overseas. As previously noted, although no one approach has been reported to be superior, increasingly there are moves towards the use of data driven approaches utilising assessment tools for budget establishment, in an attempt to ensure consistency, rationality and transparency of the fund distribution process. Within the United States recent Federal Government funding initiatives have included a requirement that States intending to access funds for disability services through the Independence Plus waiver program must use budgeting methods that are data driven (Lakin & Stancliffe, 2005; Moseley et al., 2003; Moseley et al., 2005).

Within Australia, assessment tools used for budget establishment vary across funding jurisdictions. A review conducted by the Australian Institute of Health and Welfare (AIHW, 2002c) reported that there was no standardised use of any particular assessment tool and that within the various states it was rare for any particular assessment tool to be used across the whole sector. Moseley et al. (2003), in their review of individual budgeting strategies used across the United States, also reported variability in terms of the assessment tools used by states employing data driven approaches, with some states using standardised tools, whereas others used state specific, locally developed instruments.

Assessment tools or instruments used in budgeting processes endeavour to assess the collection of skills that people require to function in various areas of their daily lives (i.e., home, community, and work). This process of functional assessment frequently involves the use of adaptive behaviour scales, such as the widely used Inventory of Client and Agency Planning (ICAP; Bruininks, Hill, Weatherman, & Woodcock, 1986) to identify the individual's functional limitations and provide a profile of an individual's support needs. The use of adaptive behaviour scales in the needs determination process underscores the close and intuitive relationship considered to exist between the constructs of adaptive behaviour and support needs.

The existence of a close relationship between adaptive behaviour and support needs is easily conceived. It would seem logical to expect that the greater the individual's adaptive behaviour deficits, the more support they are likely to need (Spreat, 1999). Guiding this expectation of a close theoretical relationship is the notion that supports and interventions are likely to be directed towards deficits in adaptive behaviour, thereby lessening the extent of limitation experienced by an individual and consequently reducing the experience of disability. Such an expectation may seem reasonable, although findings in the literature do not always provide support for this expectation. For example, within residential service settings various studies report finding that individuals with more severe disabilities actually receive less staff support (Felce & Perry, 1995; Felce & Perry, 2004; Jones et al., 1999). It is apparent from the literature that the exact nature of the relationship between the two constructs of adaptive behaviour and support needs is not yet apparent (Thompson, Hughes, et al., 2002; Thompson, McGrew, & Bruininks, 2002). Furthermore, whereas the structure of the adaptive behaviour construct has been the subject of extensive research, the structure of the support needs construct is not yet clear and the concept of support needs is not well understood, (AIHW, 2002c; Baldwin, 1986; Dyson, Vilé, & Allen 2002; MacMillan, Gresham, &

Siperstein, 1993; Mangen & Brewin, 1991; Riches, 2003; Thompson, Hughes, et al., 2002; Thompson McGrew, & Bruininks, 2002; Yeatman, 1996), and consequently warrants further investigation.

3.2 Adaptive Behaviour

3.2.1 Historical Context

Prior to the development of the first intelligence test in 1905, mental retardation (now more commonly termed intellectual disability in Australia and the United States or learning disability in the United Kingdom) was characterised in terms of deficiencies associated with social competence and vocational capacity, or what is now called adaptive behaviour (Jacobson & Mulick, 1996; Schalock & Braddock, 1999). Following the introduction of intelligence tests, the diagnostic emphasis moved from examining social and vocational competence to measuring intellectual ability; however, within 30 years the problems with this approach became apparent. Of particular concern was the adequacy of assessed IQ on its own, as a predictor of an individual's capacity to adapt socially and vocationally, with some individuals with lower IQs able to function more adequately than those with higher IQs in similar social and work environments. Responding to this concern, Doll developed a measure of social competence, the Vineland Social Maturity Scale (Doll, 1947). Guiding the development of this scale was the viewpoint that individuals diagnosed as having an intellectual disability needed to demonstrate developmental delays and social incompetency as well as low intellectual functioning (Doll, 1948). However, it was not until 1959 that the concept of adaptive behaviour was incorporated into the American Association on Mental Deficiency (AAMD) *Manual on Terminology and Classification in Mental Retardation* (Heber, 1959).

The inclusion of adaptive behaviour in the diagnostic and classification criteria for the AAMD led to the development of an adaptive behaviour instrument called the *Adaptive*

Behaviour Checklist (Nihira, Foster, Shellhaas, & Leland, 1967). The product of a comprehensive review, this scale not only included skills that were considered necessary for achieving personal and social independence (*adaptive behaviour domains)* but also addressed the types of behaviours (*maladaptive behaviour domains)* that were inhibitors in the achievement of such independence (Spreat, 1982). Maladaptive behaviours, also termed challenging or problem behaviours, included but were not restricted to socially inappropriate, and unusual or repetitious behaviours.[1] These problem behaviours have been considered important contributors to the institutionalisation, or re-institutionalisation, of individuals with intellectual disabilities (McGrew, Ittenbach, Bruininks, & Hill, 1991).

Spreat (1999) has reported that since the inclusion of adaptive behaviour in the 1959 AAMD manual, there have been over 200 adaptive behaviour scales developed and published. These scales have varied greatly in terms of:

1. Scale content, with scales varying in the range of skill areas covered in the adaptive behaviour domain and the assessment of maladaptive behaviours included in some scales but not others.
2. Depth of assessment both within and across scales, with some domains receiving extensive assessment whilst others receive less coverage.
3. Scope of instrument coverage with some scales suited to particular age groups or for use with particular levels of intellectual functioning.

The existence of so many different measures and the variations that exist within these measures is indicative of the broad range of potential skill areas that could be assessed by adaptive behaviour scales, possibly indicating a lack of clarity as to the underlying nature of the concept of adaptive behaviour (Spreat, 1999; Thompson, McGrew, & Bruininks, 1999). Another factor that has contributed to the variety of scales available is the purposes for which they were developed or used. For example, adaptive behaviour scales that are used for

[1] Maladaptive behaviours are now more frequently termed challenging behaviours or problem behaviours; however, the term maladaptive behaviour has been used in this chapter where this was the term reported in the literature discussed.

diagnostic purposes (e.g., to establish eligibility for services, benefits, or legal protections) are likely to be much shorter than scales that were designed for the purposes of planning supports or training plans for which more comprehensive skill listings would be required. Scales used for diagnostic purposes are also required to meet certain technical and psychometric standards (including reliability and validity, cultural fairness and appropriate norms), whereas scales used for the purpose of support planning would not necessarily need to meet such stringent standards (Luckasson et al., 2002; Spreat, 1999).

The requirement that both assessed intelligence and adaptive behaviour are significantly lower than would be expected for an individual's age has remained in subsequent classification manuals produced by the AAMD (later renamed as the American Association on Mental Retardation [AAMR] and more recently renamed as the American Association on Intellectual and Developmental Disabilities [AAIDD]). This presence of concurrent deficits for diagnosing an intellectual disability has also been included in other diagnostic and classification systems such as the *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV* (APA, 1994) and other legal definitions/classification systems for determining eligibility for services and/or for determining legal competency. Despite the widespread agreement regarding the importance of adaptive behaviour in the diagnosis and classification of intellectual disabilities, Luckasson et al. (2002) have stated that the concept and its measurement remain elusive. Greenspan (2003) considered that this elusiveness was associated with the inclusion of adaptive behaviour in the Heber classification system, and the subsequent development of adaptive behaviour scales, before there was an adequate "constitutive definition" (p. 5) of the adaptive behaviour construct. For some decades now, concern has been expressed about the accuracy of measuring adaptive behaviours, not only due to the vagueness of the construct, but also due to the breadth of potential skills and behaviours that would seem to be included in such a measure of human behaviour and

competency (Greenspan & Driscoll, 1997; Kamphaus, 1987; Luckasson et al., 2002; Spreat, 1999; Thompson, McGrew, & Bruininks, 2002).

3.2.2 Definition and Structure

Many attempts have been made to define adaptive behaviour over the years, in an effort to address the "vagueness" of the construct. Although differences exist between definitions there are also underlying similarities (Thompson et al., 1999). In particular, across the various definitions the emphasis usually involves the capacity for independent physical functioning and community participation; the capacity to maintain responsible social relationships; and the capacity to demonstrate age and culturally appropriate behaviours (Thompson et al., 1999). Adaptive behaviours are considered to reflect typical or day to day functioning in the individual's natural setting. Jacobson and Mulick (1996) describe adaptive behaviour as "the performance of the individual as an end product at any point of a person-environment interaction" (p. 28). Widaman and McGrew (1996) extend the notion of a person-environment interaction and add that motivational factors also impact on the performance of behaviours in day to day situations. This focus on typical performance is contrasted to the maximal performance that has traditionally been associated with measures of intellectual functioning (Widaman & McGrew, 1996).

Although there has been consensus regarding the definition of adaptive behaviour, there has been much less agreement regarding the structure that underlies adaptive behaviour. For many years researchers have used factor analytic approaches to examine the structure of adaptive behaviour. Studies have attempted to determine whether the adaptive behaviour construct is unidimensional or multidimensional. There have been numerous studies and some of these exploratory studies are summarised in Table 3.1, with the results grouped according to the overall findings regarding dimensionality.

Table 3.1 Factor Structure Studies for Adaptive Behaviour and Challenging Behaviour Scales

Study	Scale Used	Level of Measurement	Sample Characteristics	*Adaptive Behaviours*		*Challenging Behaviours*	
				No. of Factors	**Factor(s) Identified**	**No. of Factors**	**Factor(s) Identified**
Studies Reporting a Unidimensional Structure for Adaptive Behaviour							
Arndt (1981)	ABS	Factor scores	Adults with ID (3,685)	1	Adaptive Behaviour	1	Maladaptive Behaviour
Bruininks, McGrew, & Maruyama (1988)	SIB	Subscale	Adults & Children with (228) & without (1,958) ID	1	Adaptive *or* Personal Independence (secondary factors: Academic, Community/Vocational, Personal Responsibility in some age subgroups)	n/a	
Cunningham & Presnall (1978)	ABS	Subscale	Adults with ID (217)	1	Personal Independence	2	Personal Maladaptation Social Maladaptation
Godfrey et al. (1986)	ABS	Subscale	Adults with ID (210)	1	Personal Independence	2	Personal Maladaption Social Maladaption
Hug, Barclay, Collins, & Lamp (1978)	PAR	Subscale	Children without ID (148)	1	Adaptive Ability	n/a	
Katz-Garris, Hadley, Garris, & Barnhill (1980)	ABS	Subscale	Adults with ID (128)	1	Social Desirability	n/a	
Millsap, Thackrey, & Cook (1987)	ABIC	Subscale	Children with disabilities (2,085)	1	Adaptive Functioning	n/a	
Nihira (1969a)	ABCL	Subscale	Adults with ID (919)	1	Personal Independence	2	Personal Maladaptation Social Maladaptation
Nihira (1969b)	ABCL	Subscale	Children & Adolescents with ID (313)	1	Personal Independence	2	Personal Maladaptation Social Maladaptation
Stinnett, Fuqua, & Coombs (1999)	ABS-S:2	Subscale	Children with (2,074) & without (1,254) ID	1	Personal Independence	1	Social Behaviour
Thackrey (1991)	CTAB	Subscale	Adults & Children with ID (6,647)	1	Adaptive Behaviour	n/a	
Watkins, Ravert, & Crosby (2002)	ABS-S:2	Subscale	Children with (2,074) & without (1,254) ID	1	Personal Independence	1	Behaviour
Studies Reporting a Multidimensional Structure for Adaptive Behaviour							
de Bildt, Kraijer, Sytema, & Minderaa (2005)	VSF	Subscale	Children & Adolescents with ID (826)	3	Communication Daily Living Skills Socialisation	n/a	
Guarnaccia (1976)	ABS	Subscale (+ measure of productivity)	Adults with ID (40)	3-4	Personal Independence Personal Responsibility Productivity Social Responsibility	n/a	
Lambert & Nicoll (1976)	ABS-PSV	Subscale	Children with (1,461) & without (1,157) ID	2	Functional Autonomy Social Responsibility	2	Interpersonal Adjustment Intrapersonal Adjustment
Owens & Bowling (1970)	PAR	Subscale	Children with ID (100)	2	Physical Development Social-Intellectual	n/a	
Sandford & Elzinga (1987)	ABS	Subscale	Adolescents & Adults with Borderline ID (106)	3	Functional Autonomy Education Physical Development	2	Behaviour Disorder Psychiatric Disturbance
Silverstein, Wothke, & Slabaugh (1988)	MDPS	Subscale	Adults & Children with ID (8,165)	2	Motoric/Self-Help Cognitive/Social Skills	n/a	

Table 3.1 continued

Study	Scale Used	Level of Measurement	Sample Characteristics	*Adaptive Behaviours*		*Challenging Behaviours*	
				No. of Factors	Factor(s) Identified	No. of Factors	Factor(s) Identified
Studies Reporting a Multidimensional Structure for Adaptive Behaviour (continued)							
Song et al. (1984)	WBRS	Subscale	Adults & Children with ID (325); Children without ID (184)	2	Cognitive Abilities Psychomotor Abilities	n/a	
Walsh & McConkey (1989)	PIC	Subscale	Adolescents & Adults with ID (408)	3	Personal Care Daily Living Community	n/a	
Moss & Hogg (1990)	ABS	Parcel	Adults with ID (122)	2	Personal Competence Community Competence	4	Inter-Maladaptive Behaviour (or Anti-Social Behaviour) Personal Maladaptation Withdrawal Self-Injurious Behaviour
Nihira (1976)	ABS	Parcel	Adults & Children with ID (3,354)	3	Personal Self-Sufficiency Community Self-Sufficiency Personal-Social Responsibility	n/a	
Widaman, Gibbs, & Geary (1987)	CDER	Parcel	Adults & Children with ID (9,464)	4	Motor Development Independent Living Skills Cognitive Competence Social Competence	2	Social (or Extrapunitive) Maladaption Personal (or Intrapunitive) Maladaption
Gatherer & Sturmey (1991)	BAR	Item	Adults with ID (247)	2	Personal Self-Care Use of Public Amenities	n/a	
Levine & Elzey (1968)	SFVCS	Item	Adults with ID (562)	4	Cognitive Competence Cognitive & Interpersonal Flexibility Cognitive-Motor Ability Initiative-Dependability	n/a	
Nihira (1978)	ABS	Item	Children (750), Adolescents (947) & Adults (734) with ID	9-11 (vary across age groups)	Neuromotor Development Self-Help Skills Sensory Development Community Living Skills I Community Living Skills II Cognitive Development Communication Skills Speech Development Self-Direction Socialisation Personal-Social Responsibility	n/a	
Reynolds (1981)	PCS	Item	Adults with ID (481)	3	Adaptive Cognitive Affective Competence	n/a	
Silverman, Silver, Lubin, & Sersen (1983)	MDPS	Item	Adults & Children with ID (3,487)	2-8	Scale measured 1 dimension (i.e., adaptive behaviour) in 2 broad areas: Motor & Cognitive (in which the 4 subscales reflected further factors separating easy & difficult items)	n/a	
Sparrow & Cicchetti (1978)	BRIR	Item	Children with ID (45)	2	Cognitive Psychomotor	n/a	
Sparrow & Cicchetti (1984)	BIRD	Item	Children & Adolescents with ID (464)	3	Psychomotor Cognition Social	1	Control

Table 3.1 continued

Study	Scale Used	Level of Measurement	Sample Characteristics	*Adaptive Behaviours*		*Challenging Behaviours*	
				No. of Factors	**Factor(s) Identified**	**No. of Factors**	**Factor(s) Identified**
Studies Reporting on the Structure of Challenging (Maladaptive) Behaviour Only							
McGrew et al. (1991)	ICAP - PBS	Subscale	Children with ID (699); Adolescents & Young Adults with ID (5,579);	n/a		2 3	Internalised Maladaptive Externalised Maladaptive *Mild/Moderate ID:* Internalised Maladaptive Socially Disruptive Destructive General *Severe/Profound ID:* Internalised Maladaptive Externalised Maladaptive Destructive Internal
			Adults with ID (1,977)			3-4	*Mild/Moderate ID:* Internalised Maladaptive Socially Disruptive Destructive Internal Destructive External *Severe/Profound ID:* Internalised Maladaptive Socially Disruptive Destructive Internal
Aman, Richmond, Stewart, Bell, & Kissell (1987)	ABC	Item	Adults with ID (531)	n/a		5	Confirmed 5 factor structure of ABC (Irritability, Lethargy, Stereotypic Behaviour, Hyperactivity, Inappropriate Speech)
Brown, Aman, & Havercamp (2002)	ABC-C	Item	Children & Adolescents with ID (601)	n/a		4	Found 4 of the 5 ABC factors (not inappropriate speech)
Dekker, Nunn, Einfeld, Tonge, & Koot (2002)	DBC	Item	Children & Adolescents with ID (1,536)	n/a		5	Disruptive/Antisocial Self-Absorbed Communication Disturbance Anxiety Social Relating
Marshburn & Aman (1992)	ABC	Item	Children with ID (666)	n/a		4	Found 4 of the 5 ABC factors (not Inappropriate Speech)
Sturmey (2001)	ICAP-PBS	Item	Adults & Children with ID (300)	n/a		1-2	Extra-personal Maladaptive Internal Maladaptive
Sturmey, Matson, & Lott (2004)	DASH II	Item	Adults with ID (451)	n/a		5	Emotional Lability/Antisocial Language Disorder Dementia/Anxiety Sleep Disorder Psychosis

ID = Intellectual disabilities; n/a = not assessed or not included in the study

Scale Abbreviations: ABC Aberrant Behaviour Checklist; ABC-C Aberrant Behaviour Checklist–Community; ABCL Adaptive Behaviour Checklist (precursor of the ABS); ABIC Adaptive Behaviour Inventory for Children; ABS Adaptive Behaviour Scale; ABS-PSV Adaptive Behaviour Scale- Public School Version; ABS-S:2 Adaptive Behaviour Scale–School:2; BAR Behaviour Assessment Record; BIRD Behaviour Inventory for Rating Development; BRIR Behaviour Rating Inventory for the Retarded; CDER Client Development Evaluation Report; CTAB Comprehensive Test of Adaptive Behaviour; DASH II Diagnostic Assessment for the Severely Handicapped-II; DBC Developmental Behaviour Checklist; ICAP-PBS Inventory for Client and Agency Planning – Problem Behaviour Scale; MDPS Minnesota Developmental Programming System; PAR Preschool Attainment Record; PCS Personal Competency Scale; PIC Pathways to Independence Checklist; SIB Scales of Independent Behaviour; SFVCS San Francisco Vocational Competency Scale; VSF Vineland Survey Form; WBRS Wisconsin Behaviour Rating Scale.

3.2.2.1 Methodological Issues Impacting on Factor Structure Studies

As is evident in Table 3.1, the results of factor structure studies have been variable with some finding support for a unidimensional structure underlying the adaptive behaviour domains of the scales examined, although others have reported results supporting a multidimensional structure for adaptive behaviour. As well as providing insight into the controversy regarding the nature of the adaptive behaviour construct, the variability within the factor structure studies has highlighted a number of methodological issues that may have influenced outcomes in the various studies examined and, additionally, contributed to the lack of replication across various studies. Methodological/study design issues that have been reported in the literature include the following:

1. *Study participant characteristics*

Research in the area of disability frequently involves the use of samples of convenience rather than random selection of subjects for inclusion in studies. The result of this approach is participants with characteristics that may involve limited ranges (e.g., subjects of limited age range or of discrete levels of intellectual impairment, rather than a broad spectrum of ability levels) or study populations of a small size. Concern has been expressed that conducting factor analytic studies on samples with restricted demographics may limit the capacity to generalise the results (Widaman & McGrew, 1996). Various studies have undertaken sub-group comparisons within the factor structure studies to determine whether factor structures remain stable and can be replicated across sub-groups.

Level of intellectual impairment has been examined in a number of studies to determine whether factor structures vary according to the level of intellectual impairment of participants included in a study. Various authors have been able to replicate adaptive behaviour factor structures across sub-groups with different levels of intellectual impairment (Arndt, 1981; Widaman et al., 1987) or by replicating factor structures obtained for study

groups with and without intellectual disabilities (Bruininks et al., 1988; Lambert & Nicoll, 1976; Stinnett et al., 1999), although de Bildt et al. (2005) reported less differentiated structures associated with more severe levels of impairment. Despite some indications that factor structures remain consistent, McGrew and Bruininks (1989) reported that it was not clear whether level of intellectual impairment impacted on the dimensionality of factor structures for adaptive behaviour. Rather, in a review of multiple factor studies they concluded that findings with respect to the impact of degree of impairment were likely to be confounded. For example, when comparing the number of factors reported in studies involving samples with and without intellectual disabilities, there appeared to be a more multidimensional structure for adaptive behaviour associated with the intellectual disability samples; however, when analysing other study variables they concluded that these results were possibly confounded by the adaptive behaviour scale used in the studies.

Studies that have examined the impact of level of intellectual impairment on the structure of maladaptive behaviour have also reported constancy across impairment levels (Arndt, 1981; Widaman et al., 1987) and between study groups with and without intellectual disabilities (Lambert & Nicoll, 1976; Stinnett et al., 1999), although one study by McGrew et al. (1991) found variations in factor structures that indicated that maladaptive behaviours were influenced by level of intellectual impairment. As can be seen in Table 3.1, McGrew et al. (1991) reported finding different factor structure patterns associated with different severity levels of intellectual impairment. However, it was considered that the findings for externalised maladaptive behaviours were connected with characteristics of individuals within the different impairment categories. For example, less aggressive behaviour was reported for individuals with mobility impairments (which limited their capacity to act aggressively), with mobility impairments reported more frequently for individuals with profound impairments (33%) than for individuals with mild degrees of intellectual impairment (5%). Additionally,

ability to talk was understandably associated with more verbal (disruptive) behaviours compared to physical (hurts others) behaviours.

A number of studies have examined the effect of age and possible influences of *developmental stage* on the underlying factor structure of adaptive behaviour. Developmental stage is considered as potentially significant with regard to the structure of adaptive behaviours, not only because of the developmental nature of the skills and behaviours included in such scales, but also because of the potential decline of these skills associated with the ageing process. There has been some support in the literature for developmental differences in the structure of adaptive behaviour (Bruininks et al., 1988; Nihira, 1976; Nihira, 1978), although others have reported factor structures that have remained relatively constant across age groups investigated (Lambert & Nicoll, 1976; McGrew & Bruininks, 1989; Nihira, 1969a, 1969b; Silverman et al., 1983).

A large study conducted by Nihira (1976) employed a cross sectional approach to examine developmental trends and growth patterns across levels of impairment utilising the Adaptive Behaviour Scale. Nihira reported finding support for the three factors of Personal Self-Sufficiency, Community Self-Sufficiency, and Personal-Social Responsibility across the spectrum of ages examined, and considered that these factors also appeared to have a “critical period of development” (p. 226) as well as growth trends influenced by degree of intellectual impairment. For instance, the Personal Self-Sufficiency factor, which incorporates variables that assess the capacity of the individual to look after their own personal needs (e.g., toileting, eating, dressing etc.), was found to be present for all age groups investigated (i.e., from age four to 69 years of age). The Community Self-Sufficiency factor, which comprises variables associated with achieving personal independence (other than dealing with personal needs) and capacity to interact with others in social environments, was present between the ages of 10 to 69 years of age. Likewise, the Personal-Social Responsibility factor, which addresses areas

such as self-direction, responsibility, and consideration for others, also emerged in the 10 year old age group and was present throughout adulthood. Nihira also reported on a fourth factor, which was only present for children aged four to seven years of age, which was called Physical Development, comprising skills associated with motor development and appearance (i.e., posture, walking mode, clothing). Developmental trends for each of the factors varied according to level of intellectual impairment, with lower and slower rates of acquisition associated with greater levels of intellectual impairment.

Bruininks et al. (1988) found support for differences in the factor structure of adaptive behaviour associated with developmental stage. In a study using the Scales of Independent Behaviour (SIB) involving children and adults with and without intellectual disabilities, they reported that the factor analytic studies of subgroups produced a reliable finding of a large general adaptive behaviour factor, which they considered to represent Personal Independence. Factor analyses for subgroups led them to suggest differences in factor structures associated with developmental stages. In particular, they reported finding a unidimensional structure for adaptive behaviour for individuals in their school years and a multidimensional structure for those no longer involved in schooling or who had not yet commenced school. As with the findings of Nihira et al. (1976), acquisition of adaptive skills was found to be associated with different developmental stages.

With regard to maladaptive behaviour, McGrew et al. (1991) examined the impact of age on factor structure. As can be seen in the factors reported in Table 3.1, age related differences in factor structures were found. One possible explanation for the differences in factor findings included the possibility that some problem behaviours were considered less of a concern at particular age levels, resulting in different factor patterns across age groups. For example, a young child crying or screaming would not be considered as inappropriate or as disruptive as an adult displaying the same behaviours. Additionally, they cautioned that the

findings may be further confounded. For example, the broad range of behaviours that may be encompassed within any maladaptive behaviour category may lead to different factor structures across different age groups. They cited as an example two problem behaviours, pouting and law violations. Each of these behaviours would be included in the Uncooperative Behaviour Problem Behaviour scale in the instrument used in their study (i.e., Inventory for Client and Agency Planning); however, pouting is likely to be more common for children and law violations more likely to occur during adolescence. The Uncooperative Behaviour scale may then load on different factors at different age levels due to differences in the underlying nature of the presenting behaviours. McGrew et al. suggested that exposure to different life experiences and/or environmental factors may be significant in the manifestation of problem behaviours with a pattern of increasing number of factors associated with increasing age.

Sample size in factor analytic studies has received substantial attention in the literature. Recommendations regarding adequate sample size previously involved “rule of thumb” recommendations of a minimum number of subjects or specified number of subjects for each variable included in the analysis (e.g., five to 10 subjects per variable). However, recent research has indicated that these rules are not valid methods for establishing adequate sample sizes to enable recovery of factor loadings that are good estimates of the population loadings (MacCallum, Widaman, Zhang, & Hong, 1999; Sapnas & Zeller, 2002; Velicer & Fava, 1998). Instead, research by MacCallum et al. (1999) has demonstrated that sample size is dependent on variable and study characteristics. In particular, they report that level of variable communality (i.e., the proportion of variance explained by the factor structure that is associated with the particular variable) is crucial in establishing sample sizes, with high variable communalities (of .60 or greater) able to reproduce population loadings with sample sizes as small as 60 subjects and lower variable communalities requiring larger sample sizes. With regard to factor studies conducted on adaptive behaviour scales, many of the studies

included in Table 3.1 had data for large numbers of subjects for inclusion in analyses; however, there is also evidence that even when small sample numbers were used the results of these analyses were able to be replicated in larger studies. For example, the findings of a small study by Sparrow and Cicchetti (1978) were replicated in a larger study conducted by Sparrow and Cicchetti (1984).

2. *Factor analytic methods utilised*

McGrew and Bruininks (1989) have speculated that the results of factor structure studies may be confounded by the different factor method approaches utilised in studies, although the exact impact of the different approaches on factor structure results is not clear. There are a number of decisions that researchers make when undertaking a factor analysis of their data. One such decision is the *type of factor analysis* to use; in particular, whether to use an exploratory approach that is designed to identify any factor structures that may be present, or to test a specific hypothesis involving the verification of a pre-defined factor structure using confirmatory factor analysis. To date, most factor structure research has involved exploratory factor analysis in an attempt to understand the nature of the adaptive behaviour construct; however, the value of the findings of such studies is dependent on the comprehensiveness of the scales used in the study and particularly the extent to which they assess the domains considered to constitute the adaptive behaviour construct (Heal & Fujiura, 1984; McGrew & Bruininks, 1989; Widaman & McGrew, 1996).

Exploratory factor analysis is informative for building theories about the essential nature of a construct. Yet, concern exists that researchers will attempt a number of factoring models until they find a solution that fits with their hypothesis, rather than using methods that suit the nature of the dimension under investigation. For example, in exploratory factor analysis researchers can choose the *type of factoring method* they use (e.g., principal components analysis, principal axis factoring, maximum likelihood). Principal components

extraction is widely used in psychological research and is considered satisfactory if the purpose of the investigation is simply one of data reduction; conversely though, if the purpose of an investigation is to identify one or more underlying dimensions of a construct then the use of factor extraction methods, such as principal axes or maximum likelihood factor analysis, is preferred (Widaman, 1993). Although principal components extraction has been widely used in factor studies of adaptive behaviour, Widaman, Borthwick-Duffy and Little (1991) maintain that, in some circumstances, principal components extraction has resulted in higher variable loadings on factors than do principal axes factoring approaches. Of the studies in Table 3.1 that have reported the factoring methods used, 46% of studies that used principal component analysis reported finding a unidimensional structure whereas 53% reported a multidimensional structure. Of studies reporting the use of factor extraction methods, 45% reported finding a unidimensional structure and 55% a multidimensional structure. There appears to be no particular type of factoring method that accounts for the dimensionality patterns found. Nonetheless, given the concerns in the literature regarding the use of principal components extraction in this type of research, the use of principal axes or similar factor extraction methods would be advisable.

Further considerations for researchers using exploratory factor analysis involve the process for determining the number of factors to retain and the rotation method to be used to obtain factor loadings. With regard to the *number of factors to be retained,* rather than relying on the eigenvalues greater than or equal to one rule (Kaiser, 1960), which has been widely used in factor analytic research, Widaman and McGrew (1996) suggested the use of additional methods such as the scree test (Cattell, 1966) or the parallel analysis criterion (Widaman et al., 1987). The eigenvalue rule has been criticised as lacking consistency as an indicator of the number of factors to retain, with some suggesting it underestimates the actual number of factors present although others consider it overestimates the number of factors

present (Preacher & MacCallum, 2003). Not all studies in Table 3.1 reported the method used for determining the number of factors to retain; however, for those studies for which the information was available, the following percentages were obtained. Factor retention methods for studies finding a uni-dimensional structure for adaptive behaviour included: scree test (12%); eigenvalues greater than one rule (50%); combined more than one method (25%); and other method (12%). Factor retention methods used in studies reporting a multidimensional structure for adaptive behaviour included: scree test (17%); eigenvalues greater than one rule (50%); combined more than one method (33%). No one factor retention method was associated with studies reporting a uni- or a multi- dimensional factor structure for adaptive behaviour. In their review of factor studies of adaptive behaviour, McGrew and Bruininks (1989) concluded that it was not possible to state clearly the impact of factor retention approaches on the findings with respect to dimensionality of adaptive behaviour, but cautioned that it may be a confounding factor in this type of research.

Having established the number of factors to retain, the researcher must then decide which *method of rotation* should be used to enable interpretation of the factors. Factors may be rotated in two ways. Orthogonal rotations result in factors that are uncorrelated whereas oblique rotations produce factors that may be correlated. The choice of which factor rotation to use "depends on whether there is a good theoretical reason to suppose the factors should be related or independent" (Field, 2003, p. 439). Not all studies in Table 3.1 reported the type of factor rotation approach used. Of the studies reporting a unidimensional structure for adaptive behaviour, 63% reported using an orthogonal (i.e., uncorrelated) rotation method compared to 25% that used an oblique rotation method, with 12% of studies using more than one method. For studies finding a multidimensional structure for adaptive behaviour, 44% used orthogonal rotations, 44% of studies used oblique rotation methods and 12% of studies used more than one method. Although a number of factor structure studies on adaptive behaviour have used

orthogonal rotations, these are generally not considered appropriate for research on domains such as adaptive behaviour due to the likelihood of correlations existing between identified factors, with oblique rotations preferred (Nihira, 1976; Widaman & McGrew, 1996; Widaman et al., 1991).

A further consideration for researchers undertaking factor analysis is the *measurement level* they intend to use in the factor analysis. The levels of measurement that can be used in factor studies of adaptive behaviour include entering item level data, grouping items into parcels for inclusion in the analysis or entering subscale scores. McGrew and Bruininks (1989) reported that the number of adaptive behaviour factors identified in an analysis was related to the number of variables entered into an analysis, finding a significant correlation of .86. McGrew and Bruininks further investigated the impact of measurement level by examining factor studies for a single instrument, in particular the Adaptive Behaviour Scale, which had been analysed at each measurement level. They reported that subscale studies had found one to three factors solutions; parcel level analyses found three to four factor solutions; and item level analyses found nine to ten factor solutions; and the significance of these relationships were supported by multiple regression. The finding of an association between level of measurement and number of identified factors was supported in a similar review conducted by Thompson et al. (1999). Mean values for the number of factors found revealed a trend of more factors reported for factor analyses using item level data compared to analyses that used subscale level data. In particular, the mean factor values obtained were 1.6 factors for subscale analyses, 3.4 factors for parcel studies, and 6.3 factors for item studies. Thompson et al. reported that 74% of variance associated with the number of factors obtained was associated with the measurement level of the variables used in the factor analysis.

This pattern is evident in Table 3.1. All studies reporting a unidimensional structure for adaptive behaviour used subscale or factor level of measurement in the factor analyses

conducted, with no item level analyses reporting a unidimensional structure. When considering the studies reporting a multidimensional structure for adaptive behaviour, factor studies using item level analyses produced between two and 11 adaptive behaviour factors, whereas subscale and parcel factor studies produced between two and four factors. It is worth noting that in the study by Guarnaccia (1976) an additional productivity measure was included as well as the adaptive behaviour subscales, with this addition likely to be significant in the finding of the fourth productivity factor.

Two possible explanations have been offered for the finding of an association between measurement level and number of factors identified. Either the result could be evidence that the underlying factor structure of adaptive behaviour is complex and findings reported in the literature were confounded by the approaches used for the factor analyses (McGrew & Bruininks, 1989) or, the different results obtained using subscale, parcel or item analyses may be supportive of the existence of a hierarchical model for adaptive behaviour, much like that suggested for models of intelligence (McGrew & Bruininks, 1989; Thompson et al., 1999; Widaman & McGrew, 1996; Widaman et al., 1991). That is, analysing large numbers of items is likely to result in more numerous lower order factors, whereas analyses that used subscales were more likely to find a smaller number of higher order factors that incorporate the areas measured by the lower order factors (see Figure 3.1). Further research is indicated regarding the possible hierarchical structure of adaptive behaviour. In terms of the measurement level employed in this type of research, McGrew and Bruininks suggested that subscale level analyses provided the best basis for examining the factor structure of adaptive behaviour. However, Widaman and McGrew cautioned that, for each factor the researcher is aiming to identify, at least three indicator variables must be included in the procedure.

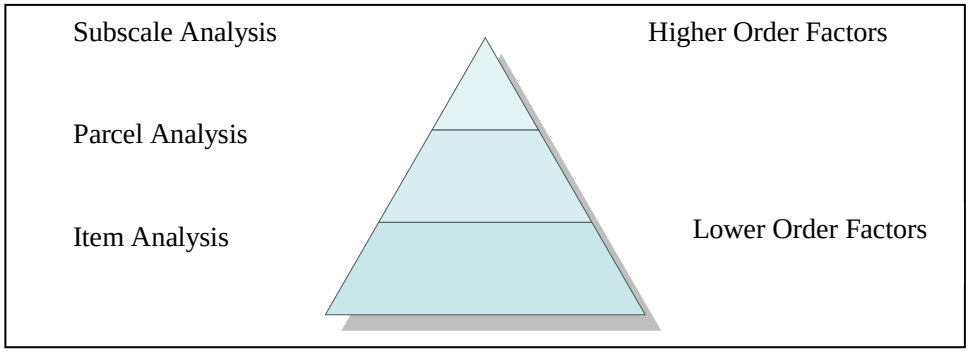


Figure 3.1. Suggested hierarchical structure of adaptive behaviour.

3. *Adaptive Behaviour Scales Investigated*

As can be seen in Table 3.1, a number of different scales have been used in factor structure studies. Various authors have speculated about the effect of using such a range of adaptive behaviour scales in research aimed at identifying the factor structure of the construct, given that no single adaptive behaviour scale measures all of the potential dimensions of adaptive and maladaptive behaviours, with different scales giving more or less breadth of coverage to different domains (Harrison, 1987; Thompson et al., 1999; Widaman & McGrew, 1996). With regard to the scales used in factor structure studies, Widaman et al. (1991) considered that not only were the psychometric properties of an instrument important but also the breadth of coverage of domains areas, with some scales using single items to address skill areas covered by a whole subscale in other adaptive behaviour instruments. They cautioned that the use of subscale analyses may not produce reliable replication of factor structures if the subscales from various adaptive behaviour instruments are not similarly constituted with regard to breadth and scope of coverage.

With regard to the dimensionality of the adaptive behaviour construct, McGrew and Bruininks (1989) examined the association between the number of factors obtained and the scale used in the studies. Although finding what appeared to be an association between the scales used and the number of factors identified, they considered it possible that the findings were a function of the measurement level used in the factor studies. Thompson et al. (1999)

further confirmed this when examining the number of factors obtained in studies that used the Adaptive Behaviour Checklist and the revised version of this instrument, the Adaptive Behaviour Scale. With regard to the mean number of factors obtained at each level of measurement, they found a mean for subscale analyses of 1.9 factors identified, for parcel level analyses they obtained a mean of 2.5 factors identified, and 7.3 factors identified for item level analysis. These figures were largely consistent with the pattern of results reported earlier for subscale, parcel and item level measurements involving a range of adaptive behaviour instruments, indicating that it was likely that measurement level rather than the instrument used that was important in influencing the number of factors identified.

4. *Terminology*

Efforts to identify the structure of adaptive behaviour construct have been hindered by the fact that the terminology used for describing adaptive behaviour domains has been inconsistently applied, with researchers describing similar domains with different terminology, and likewise for the naming/identification of factors obtained during analyses (Widaman & McGrew, 1996).

3.2.2.2 Reviews of Factor Structure Studies

The studies reported in Table 3.1 represent examples of studies that have been undertaken to examine the factor structure of adaptive behaviour. It is apparent from examining the findings of these studies, and from the discussion of methodological concerns above, that the issue of resolving the structure of the adaptive behaviour is complex and complicated. In attempts to bring some clarity and to achieve some accord regarding the underlying structure of adaptive behaviour, there have been five major reviews of factor analytic studies of adaptive behaviour reported in the literature. Within these reviews, multiple factor studies have been considered, with the authors examining the findings in terms of unique and similar findings and with regard to the methodological factors discussed above.

The first major review was completed by *Meyers, Nihira and Zetlin (1979).* In this review, they considered eight factor structure studies. Five of these studies examined adaptive behaviours only. Instruments used in the studies included the San Francisco Vocational Competency Scale (study conducted by Levine & Elzey, 1968), the Fairview Self-Help Scale (study conducted by Ross, 1970 as cited in Meyers et al., 1979), the Preschool Attainment Record (study conducted by Owens & Bowling, 1970), and two studies used the Adaptive Behaviour Scale (studies conducted by Guarnaccia, 1976 and Nihira, 1976). Three studies examined both adaptive and maladaptive behaviours, with the Adaptive Behaviour Scale used in all three studies (Lambert & Nicoll, 1976; Nihira, 1969a, 1969b).

Of the studies examined in this review, only the early investigations by Nihira (1969a, 1969b) using the Adaptive Behaviour Checklist reported finding a single factor structure for adaptive behaviour. Meyers et al. noted that subsequent analyses by Nihira (1976) involving the Adaptive Behaviour Scale (the successor of the Adaptive Behaviour Checklist) produced a three factor solution yet differed from the earlier analysis because Nihira used an oblique factor rotation method in the latter analyses, rather than the orthogonal method used in the earlier studies. The remaining five adaptive behaviour factor studies were reported as finding between two and four factors present. Meyers et al. concluded that there appeared to be two dimensions underlying adaptive behaviour, the first dimension they labelled *Autonomy,* including factors obtained in the studies that had been called Functional Autonomy, Personal Independence, Personal Self-Sufficiency, Community Self-Sufficiency, Cognitive-Motor Ability, Cognitive Competence, and Physical Development. The second dimension they labelled as *Responsibility,* which included factors reported in the studies called Social Responsibility, Personal-Social Responsibility, Initiative, Dependability, Cognitive-Interpersonal Flexibility, and Social Intellectual. With regard to maladaptive behaviour, they found support for two factors: *Social Maladaptation* involving “extrapunitive antisocial

aggression" (p. 459) and *Personal Maladaptation* involving "intrapunitive, autistic behaviours" (p. 459). They concluded that adaptive behaviour did not appear to be a "unitary trait" (p. 465) that could be represented by a single score on an adaptive behaviour scale.

The next major review was conducted by *McGrew and Bruininks (1989).* This review examined 16 studies that were required to fit certain review inclusion criteria. In particular, to be included in the review, factor studies needed to be exploratory in nature; that is, not restricting the possible factor structure or numbers, as would be the case when confirming instrument design or subscale structure, (e.g., the studies by Sparrow and Cicchetti, 1978 and Sparrow and Cicchetti, 1984). Additionally, sufficient variables were required to enable more than one factor to be identified. In view of the finding by Meyers et al. (1979) of a possible two factor structure and the requirement that at least three variables were required to identify a factor, this meant studies needed to include at least six variables to be incorporated in the review.

McGrew and Bruininks investigated the impact of a number of methodological issues that were considered to be complicating the process of understanding the underlying structure of adaptive behaviour, including sample and scale characteristics as well as factor analytic methods used. A significant finding of this review was the association between number of factors obtained and level of measurement used in the study. In an attempt to address the impact of measurement level, they focused subsequent examinations on studies that had used subscale analyses only, as had been used for undertaking factor analyses of intelligence tests.

With respect to the dimensionality of adaptive behaviour, McGrew and Bruininks concluded that there was support for a large general factor that they called *Personal Independence.* They considered that this factor was generally the first large factor obtained by researchers undertaking factor analyses on subscales of adaptive behaviour scales. This factor had been variously termed by investigators as Functional Autonomy, Adaptive Ability,

Adaptive Functioning, Social Intelligence, Cognition, and Social Desirability in the studies examined. They also reported that, in addition to the Personal Independence factor, other secondary factors were sometimes reported. Although these secondary factors were not replicated in all of the studies reviewed, they termed these factors *Responsibility* or *Social/Interpersonal*, *Functional Academic/Cognitive*, *Vocational/Community* and *Physical/Developmental*. With regard to maladaptive behaviours they found support for the two factors reported by Meyers et al. (1979) in all but one of the studies reviewed; however, they cautioned that further research was required utilising other scales measuring maladaptive behaviours, because these results had largely been derived using the Adaptive Behaviour Scale, as was the case in the Meyers et al. review. In view of the findings of up to five factors they suggested that the structure of adaptive behaviour was likely to be multidimensional and suggested that future investigations should consider a hierarchical model for adaptive behaviour and that item and parcel level studies may provide illuminating data in the investigation of such a model.

Widaman, Borthwick-Duffy and Little (1991) conducted a further review of adaptive behaviour factor studies but included studies at all levels of measurement. Although acknowledging the effect of measurement level on the results of factor studies, they examined the findings of various factor studies in terms of a broader range of methodological issues that may have contributed to the study findings. When reviewing studies that had reported unidimensional structures for adaptive behaviour, they identified methodological issues that they reported may have been significant in contributing to findings of a single factor structure. For example, they cited examples of studies that they considered used scales that either contained small numbers of subscales or insufficient indicator variables to enable multiple factors to be identified, such as the studies by Bruininks et al. (1988), Hug et al. (1978) and Millsap et al. (1987). Further, they expressed concern regarding the lack of adequate reporting

of factor analytic methods employed to enable adequate evaluation of findings, for example they cited the studies of Hug et al. (1978) and Katz-Garris et al. (1980). Additionally, they questioned the appropriateness of the factor analytic methods used, particularly the use of principal components analysis, orthogonal rotation and factor retention procedures involving the use of eigenvalues; for example, the study by Bruininks et al. (1988).

When examining findings of studies that had reported multidimensional factor structures for adaptive behaviour, Widaman et al. reported on similar methodological issues and their likely impact on results. For example, as reported above, some instruments used in studies finding multidimensional structures were considered to contain item content that was restricted or not sufficiently representative to enable factors to be extracted or to provide adequate separation of factors. In this regard, they cited the studies by Levine and Elzey (1968), Reynolds (1981), Silverman et al. (1983), Song et al. (1984), and Walsh and McConkey (1989). In two studies, sample size was considered to be too small, particularly given the nature of the statistical analyses, such as Guarnaccia (1976) and Sparrow and Cicchetti (1978); however, as previously noted Sparrow and Cicchetti (1984) subsequently replicated their findings with a larger sample. They considered that a broad age range was a possible contributor to low dimensionality for one study; for example the study by Owens and Bowling (1970). Furthermore, difficulties in interpreting the findings of studies due to the insufficient detail provided on the findings, such as in the studies by Lambert and Nicoll (1976) and Nihira (1978), or factor analytic methods used, as in the studies by Sparrow and Cicchetti (1978, 1984), hampered proper exploration of the factor structure findings.

Notwithstanding the methodological issues inherent in the factor studies considered (i.e., sample characteristics, scale characteristics, and features of the factor analytic method used), they concluded that there was support for a multidimensional adaptive behaviour structure and were in agreement that further research was warranted to address the differences

reported between studies that may be pointing to a hierarchical structure. They speculated that the structure of adaptive behaviour may be similar to the hierarchical structure suggested for other areas of "mental abilities" (p. 18) involving broad general factors at upper levels of the hierarchy with narrow specific factors at lower levels. As such, they considered that the uni- and multi- dimensional outcomes of studies may both be accurate and reflect the possible hierarchical structure as well as being related to the level of measurement used in studies.

Additional support for a multidimensional and hierarchical structure was discussed in terms of correlations between factors obtained in one study included in this review, and that was the study by Widaman et al. (1987). As indicated in Table 3.1, Widaman et al. identified four factors, Motor Development, Independent Living Skills, Cognitive Competence and Social Competence, which were found to be moderately correlated. Widaman and McGrew suggested that the correlations offered support for the existence of a higher order Personal Independence factor, yet the degree of intercorrelation was low enough to suggest the four factors were reflecting separate dimensions of adaptive behaviour. Additionally, the correlations between the two maladaptive factors identified, Social (or Extrapunitive) and Personal (or Intrapunitive) Maladaption, may be indicative of a higher order *General Maladaption* factor.

Widaman and McGrew (1996) conducted a further review of adaptive behaviour that differed from previous reviews in that it considered both exploratory and confirmatory factor analysis studies. The review of exploratory factor studies largely reflected those reported in earlier reviews, with similar methodological issues raised (e.g., level of measurement employed in the analysis, factor analytic methods, comprehensiveness of scale items, use of different naming terminology etc.). Additionally, five studies were examined that employed confirmatory factor analytic approaches to test the multidimensional structure of adaptive behaviour. These studies provided support for a multidimensional structure for adaptive

behaviour. In terms of the dimensions underlying adaptive behaviour, they found support for four dimensions that were named "a) motor or physical competence (or development); b) independent living skills, daily living skills, or practical intelligence; c) cognitive competence, communication, or conceptual intelligence; and d) social competence or social intelligence" (p. 109), although they noted that scales varied in the extent to which they covered the identified dimensions. Widaman and McGrew noted that these dimensions of adaptive behaviour were consistent with the four components of the model of personal competence put forward by Greenspan and Grandfield (1992). In terms of dimensions of adaptive behaviour that have been identified in earlier factor analytic reviews and examinations of adaptive behaviour (e.g., by Kamphaus, 1987), they did not find support for responsibility and vocational dimensions. They suggested that this finding may be related to the inadequate assessment of the vocational domain in many adaptive behaviour scales, making the identification of a specific vocational factor less likely. Further, they suggested that responsibility (and motivation) was not identified as a separate dimension of adaptive behaviour as it was "an implicit component of many adaptive behaviour items" (p. 109) that was embedded within other adaptive behaviour dimensions. As with previous reviews they found support for two maladaptive behaviour factors. Although supporting the multidimensional structure, they also considered that the unidimensional findings in some studies were relevant and indicators of a possible hierarchical structure.

The most recent review of adaptive behaviour factor structure has been undertaken by *Thompson, McGrew and Bruininks* (*1999).* As with previous reviews, certain inclusion criteria were employed. In particular, studies included needed to have factored at least six variables to allow adequate factor identification. Additionally, factor analysis needed to have been conducted on at least one sample of participants with intellectual disabilities (or for studies where disability characteristics were not clear, the scale must have been designed for

use with individuals with intellectual disabilities). Thirty one studies were included in this review, which enabled analysis of factor findings for 86 samples, with all levels of measurement (i.e., item, parcel and subscale studies) initially included. As mentioned previously, using this extended sample of studies Thompson et al. also found an association between level of measurement and number of adaptive behaviour factors identified. This finding was not thought to be associated with the scale used in the studies but rather was considered to inform the possible hierarchical structure for adaptive behaviour.

With regard to the dimensionality of adaptive behaviour, using the findings of parcel and subscale studies, they found support for a multidimensional structure. Strong support was obtained for the three dimensions of, "personal independence (e.g., functional autonomy, self-sufficiency, independent functioning), responsibility (e.g., meeting expectations of others and/or getting along with others in social contexts), and cognitive/academic (e.g., functional time, number, and literacy skills)" (p. 26). Additionally, some support was also found for a further two dimensions: "physical/developmental (e.g., physical and health aspects of perceptual/motor skills; locomotion/ambulation) and vocational/community (e.g., effective skills in community, job, career, work settings)" (p. 26). These findings were largely consistent with findings of McGrew and Bruininks (1989) who also reported finding support for five dimensions, and they were also very similar to the four dimensions of adaptive behaviour reported in the review by Widaman and McGrew (1996) and those obtained in the study by Widaman et al. (1987).

When examining the factor structure of maladaptive behaviour, as with previous reviews Thompson et al. reported an association between number of factors obtained and the level of measurement, finding that measurement level accounted for 47% of the variance associated with the number of factors identified. Using parcel and subscale studies, they classified maladaptive factors identified in the studies. As with all previous reviews they also

found support for the conclusion that maladaptive behaviours can be classified into two categories, these being personal (intrapunitive) and social (extrapunitive) problem behaviours, with other identified factors possibly representing lower level factors that can be subsumed within these two broad factors.

The dimensions reported in this and earlier reviews have provided empirical support for the most recent definition of adaptive behaviour given in the American Association on Intellectual and Developmental Disabilities (AAIDD) *Definition, Classification, and System of Supports*, which defines adaptive behaviour as "the collection of conceptual, social, and practical skills that have been learned by people in order to function in their everyday lives" (Luckasson et al., 2002, p. 14). Although the reviews of factor studies for adaptive behaviour have generally reported more than three dimensions (or factors), Luckasson et al. considered that the conceptual, social, and practical skill dimensions closely matched the "higher order dimensions" (p. 76) frequently reported. Table 3.2 demonstrates the congruence between the adaptive behaviour dimensions of the 2002 AAIDD definition of adaptive behaviour and the factors identified in the factor analytic reviews.

Table 3.2 Congruence between the 2002 AAIDD Dimensions of Adaptive Behaviour and Empirically Derived Factors Identified in Factor Analytic Reviews.

AAIDD Dimensions	***McGrew & Bruininks (1989)***.	***Widaman & McGrew (1996)***	***Thompson, McGrew & Bruininks (1999)***.
Conceptual Skills	Functional Academic or Cognitive	Cognitive Competence, Communication, or Conceptual Intelligence	Cognitive/Academic
Social Skills	Responsibility or Social/Interpersonal	Social Competence or Social Intelligence	Responsibility
Practical Skills	Personal Independence Vocational/Community	Independent Living Skills, Daily Living Skills, or Practical Intelligence	Personal Independence Vocational/Community
Health	Physical/Developmental	Motor or Physical Competence (or Development)	Physical/Developmental

Although the three dimensions of adaptive behaviour are not defined in the 2002 AAIDD Definition, Classification, and System of Supports manual, examples of skills associated with these dimensions are supplied. Examples provided are as follows:

1. Conceptual: Language (Receptive and Expressive); Reading and Writing; Money Concepts; Self-Direction.
2. Social: Interpersonal; Responsibility; Self-esteem; Gullibility (likelihood of being tricked or manipulated) ; Naiveté; Follows Rules; Obeys Laws; Avoids Victimisation.
3. Practical: Activities of daily living (Eating, Transfer/mobility, Toileting, Dressing); Instrumental activities of daily living (Meal preparation, Housekeeping, Transportation, Taking medication, Money management, Telephone use); Occupational Skills; Maintains Safe Environments. (Luckasson et al., 2002, p. 42)

This 2002 AAIDD definition of adaptive behaviour, with its focus on the underlying dimensions of adaptive behaviour, is a departure from the previous 1992 AAIDD definition of adaptive behaviour that had a focus on adaptive skills, with 10 specific skill areas described (i.e., Communication, Self-Care, Home Living, Social Skills, Community Use, Self-Direction, Health And Safety, Functional Academics, Leisure, and Work). In keeping with the hierarchical structure thought to underlie adaptive behaviour, it is considered that these skills can be conceptually encompassed within the three dimensions of the 2002 definition of adaptive behaviour. The fourth factor found in many factor analytic studies, Motor or Physical Competence (involving ambulating, gross and fine motor skills), is not included within the adaptive behaviour dimension by the AAIDD but instead is measured within a separate Health dimension (Luckasson et al., 2002), as indicated in Table 3.2.

The Health dimension is one of five dimensions incorporated in the AAIDD's 2002 classification model that forms the basis of the multidimensional approach to understanding intellectual disability. The Health dimension is conceptualised as including physical health,

mental health, social well-being and aetiological factors. Consequently, it not only encompasses aspects of physical competence (i.e., ambulating, gross and fine motor skills etc.) that are frequently assessed in adaptive behaviour scales, but also includes behavioural disturbances that may arise due to underlying health concerns (e.g., head banging due to headaches, or infections) and behavioural disturbances (that may be due to the presence of a mental health condition). These types of behaviours are frequently assessed in maladaptive domains of adaptive behaviour instruments. A number of adaptive behaviour instruments include some assessment of maladaptive, challenging or problem behaviours, although generally the scores are interpreted separately.

Correlations between adaptive and maladaptive domains are usually reported to be low (i.e., $r < .25$) (Luckasson et al., 2002). Some factor structure studies have reported finding factors that have loading patterns involving variables from both adaptive and maladaptive domains (i.e., adaptive behaviour factors with positive loadings for the adaptive variables and negative loadings for the maladaptive variables or maladaptive behaviour factors with negative loadings for the adaptive variables and positive loadings for the maladaptive variables) (Lambert & Nicoll, 1976; Nihira, 1969b; Stinnett et al., 1999; Watkins et al., 2002). Roszkowski, Spreat, and Waldman (1983) used canonical correlation to examine the degree of overlap between adaptive and maladaptive behaviours on the Adaptive Behaviour Scale (ABS). They reported finding three dimensions that explained the overlap; in particular, intellectual ability, sociability and physical ability. With respect to intellectual ability, they reported both positive (i.e., subscales associated with extrapunitive maladaptive behaviours more typical of individuals with less severe levels of intellectual disability) and negative (i.e., subscales associated with intrapunitive maladaptive behaviours more typical of individuals with more severe levels of intellectual disability) loadings for maladaptive behaviour items and the adaptive behaviour subscales considered to be consistent with intellectual ability (e.g.,

Language Development, Numbers and Time, etc.). With respect to sociability, they reported positive loadings for the Socialisation and Self-Direction subscales and negative loadings for the Withdrawal subscale, indicating that these adaptive and maladaptive behaviour subscales were measuring the "positive and negative poles of the same attribute" (p. 226). The physical ability dimension involved positive loadings for the Physical Development adaptive behaviour subscale and all maladaptive subscales except Withdrawal, with Hyperactivity loading most strongly. Despite these studies, which have reported overlap between adaptive and maladaptive behaviour domains, generally the evidence from the factor structure studies is that these behaviour domains are separate and discrete constructs (McGrew & Bruininks, 1989; McGrew et al., 1991; Meyers et al., 1979; Widaman, Stacy, & Borthwick-Duffy, 1993). Nevertheless, the hypothesised hierarchical and multidimensional structure considered to underlie both maladaptive and adaptive behaviour, has been conceptually likened to the multidimensional and/or hierarchical structure considered by some theorists to be underlying intellectual abilities. Such similarity lends support to the possibility that intellectual abilities, adaptive and maladaptive behaviours could be incorporated within a broader model of human abilities or personal competence (Schalock, 1999; Thompson et al., 1999).

3.2.3 Relationship to Models of Personal Competence

The relationship between adaptive behaviour and intelligence, where intelligence is thought to reflect a person's abstract reasoning and thought processes, has been frequently addressed and it has been suggested that the level of intelligence mediates quality of adaptation (Grossman, 1983). Although correlations between scores obtained on adaptive behaviour and intelligence scales vary according to the type of scale used and across samples, the coefficients are generally in the moderate range (Harrison, 1987; Meyers et al., 1979). There is growing evidence that the two constructs are interrelated and that, rather than being considered as separate entities, intelligence and adaptive behaviour overlap and should be

merged within a larger framework of human abilities (Schalock, 1999; Thompson et al., 1999).

As with adaptive behaviour, current theories of intelligence have moved away from the idea of one general factor as a sufficient description; and instead consider there to be multiple intelligences (Gardner, 1993; Sternberg, 1988; Thurstone, 1938) and/or models of intelligence that are hierarchically structured (Carroll, 1993; Horn & Cattell, 1966; Vernon, 1950). However, the model that is frequently used to conceptualise the merging of adaptive behaviour and intelligence into a framework of human abilities is the Personal (or Personal-Social) Competence model (Greenspan, Switzky, & Granfield, 1996). The conceptual similarities between the multiple intelligences contained within this model of intelligence and the findings of the adaptive behaviour factor structure studies reported previously (McGrew & Bruininks, 1989; Thompson et al., 1999; Widaman & McGrew, 1996; Widaman et al., 1991), support the use of this model for developing such a framework (Schalock, 2003; Thompson et al., 1999).

The personal competence approach to intelligence is a model that contains the three elements of conceptual intelligence, social intelligence and practical intelligence. The personal competency model has been acknowledged as similar to Thorndike's tripartite model of intelligence, which was put forward in 1920 and consisted of abstract intelligence, social intelligence and mechanical intelligence (Greenspan & Driscoll, 1997). Within the personal competency model *Conceptual Intelligence* (i.e., academic or analytic intelligence) refers to an individual's capacity to solve abstract problems and to use language. It is this aspect of intelligence that is assessed by traditional IQ tests and that is most closely associated with academic success. *Practical Intelligence* corresponds to Thorndike's mechanical intelligence and encompasses the individual's capacity to deal with the physical aspects of life such as daily living skills, self-maintenance and vocational pursuits. It is this element of intelligence

that is considered to be largely assessed using adaptive behaviour scales and is the area of intelligence that predicts success in independent living and the non-social aspects of work. *Social Intelligence* refers to the individual's capacity to understand and deal with social and interpersonal events and situations (Greenspan, 2003; Mathias & Nettelbeck, 1992; McGrew, Bruininks, & Johnson, 1996; Schalock, 2003).

For many years Greenspan has expressed concern that major diagnostic systems have failed to recognise the importance of deficits in social intelligence for individuals with intellectual disabilities (Greenspan & Driscoll, 1997; Greenspan & Granfield, 1992). Most major diagnostic systems have used the dual criteria of deficits in IQ (conceptual intelligence) and adaptive behaviour (largely practical intelligence), with Greenspan contending that both instrument types lack adequate coverage of the social domain (Greenspan, 2003). Greenspan attributes the inadequate coverage of social competencies in adaptive behaviour scales to an absence of an adequate conceptual model at the time when adaptive behaviours were first incorporated in the diagnostic systems and to guide the development of scales, although deficits in this area have been long recognised as important in defining the nature of intellectual disabilities (Greenspan, 1999a, 1999b; Thompson, McGrew, & Bruininks, 2002; Widaman et al., 1987). The recent change in the AAIDD definition of adaptive behaviour, to include the more global concepts of conceptual, practical and social skills, represents acknowledgement of the importance of social intelligence in defining the nature of intellectual disabilities and recognises the need to merge the concepts of intelligence and adaptive behaviour within a larger schema of overall or personal competence (Thompson, McGrew, & Bruininks, 2002).

Greenspan's model of personal competency has evolved overtime. In addition to the three dimensions of intelligence discussed above, the original model of personal competence also included two additional dimensions: socio-emotional adaptation and physical

competence. *Socio-emotional adaptation,* later called emotional competence, incorporated variables associated with character and temperament, similar to those items found in maladaptive behaviour scales (McGrew & Bruininks, 1990; McGrew et al., 1996). *Physical competency* incorporated areas associated with physical growth and development, motor skills and health. Investigations to test the validity of this model include an exploratory factor analysis study by Mathias and Nettelbeck (1992), which found support for a factor that appeared to correspond to conceptual (or verbal) intelligence but failed to find support for the presence of a separate social intelligence factor. Rather, they found that social and practical intelligence formed one factor (termed Practical-Interpersonal Competence). Greenspan and McGrew (1996) conducted a reanalysis of Mathias and Nettelbeck's data using confirmatory factor analysis and reported finding support for separate social and practical intelligence factors, although Mathias and Nettelbeck considered a single factor solution equally viable (Mathias, Nettelbeck, & Willson, 1996). Another confirmatory factor analysis study by McGrew and Bruininks (1996) found support for the dimensions of practical, social, and conceptual intelligence as well as emotional competence (maladaptive behaviour). They did not find support for the Practical-Interpersonal Competence factor found by Mathias and Nettelbeck (1992), nor did they find support for a single social-emotional competence factor, as presented in the original Greenspan model discussed above. An earlier study by McGrew and Bruininks (1990), although not investigating the presence of social competence, did find support for the dimensions of practical, conceptual, emotional and physical competence, although they did suggest that a less differentiated model of personal competence may be required for the early childhood years.

The most recent version of Greenspan's model of personal competence (Greenspan & Driscoll, 1997) varies slightly from that described previously. It comprised four dimensions each with two subdomains (indicated in brackets): *physical competence* (organ and motor

competence); *affective competence* (temperament and character); *everyday competence* (social and practical intelligence); and *academic competence* (conceptual intelligence and language). The subdomain areas are further subdivided into more narrow dimensions. Further research is required to test the validity of this model; however, inhibiting this research is the availability of appropriate assessment tools, particularly, instruments design to test maximal performance in the areas of social and practical competence (Greenspan, 1999a; Thompson, McGrew, & Bruininks, 2002).

3.3 Adaptive Behaviour Summary

Despite many decades of use and research, our understanding and definitions of adaptive behaviour are continuing to change. Significant in these changes are attempts to position adaptive behaviour within a framework of personal competence. Various researchers have proposed personal competency frameworks for conceptualising, investigating and interpreting the structure of human abilities and for understanding intellectual disabilities (Greenspan & Driscoll, 1997; McGrew & Bruininks, 1990; Schalock, 1999; Thompson et al., 1999). Thompson et al. suggested that such a framework could be used for developing maximal and typical performance assessment approaches, thereby ensuring comprehensive coverage of the dimensions of personal competence. Presently, adaptive behaviour scales, although varying in content across scales, provide assessment of typical performance across a number of dimensions of personal competence. Although the dimensions vary slightly across models, in general the following dimensions of personal competence are measured in adaptive behaviour scales: Practical Intelligence (e.g., self-care, home-living, community, work, leisure etc.); Social Intelligence (e.g., cooperation, responsibility, assertion etc.); Conceptual Intelligence (e.g., functional academics); Physical Competency (e.g., fine and gross motor skills, mobility, ambulation); and Emotional Competence (e.g., maladaptive behaviour assessment) (Thompson et al., 1999). Thompson, McGrew, and Bruininks (2002) suggested

that developers of future adaptive behaviour scales should ensure adequate coverage across the personal competence dimensions. They suggested renaming scales in a manner that reflects this content (e.g., “typical competence behaviour or everyday competence” p. 33).

Chapter 4. Support Needs and Key Assessment Issues

4.1 Contemporary Models of Disability

Traditionally, adaptive behaviours have been used to identify the deficits an individual has for diagnostic, classification or eligibility purposes. Generally, they represented a "snapshot" of the individual's typical level of functioning at a particular time. This form of assessment is consistent with the model of disability that was prevalent at the time adaptive behaviour scales were first developed. The *medical model* viewed disability as a characteristic of the individual that resulted from a health condition, disease or trauma and that required medical treatment or intervention to resolve the problem. Such a deficit based approach has been criticised as resulting in the exclusion of individuals from participation in activities due to the existence of these deficits (Kirby et al., 2004), and is contrasted to contemporary approaches to understanding disability, in which disability is considered to be an interaction between the characteristics of the individual and the context in which they live, called a *bio-psycho-social model*. It is this model that underlies the World Health Organisations (WHO) *International Classification of Functioning, Disability and Health* (ICF; WHO, 2001).

Within the ICF model an individual's state of functioning is considered to be a dynamic interaction between 1) the individual (and their health condition or impairment), 2) the activities they wish to participate in, and 3) contextual factors that may either restrict or facilitate participation. These contextual factors include *environmental* or *personal* factors that may be exerting an influence on the individual. Environmental influences are factors that are external to the individual. They constitute elements of the individual's background that may be exerting either a positive (facilitating) or a negative (hindering) influence on the individual's state of functioning. Environmental factors include a broad range of physical, social and attitudinal characteristics of the individual's environment. Within the ICF, environmental factors are directed at either the individual or the societal level. At the

individual level, environmental influences may include physical features confronting the individual within their immediate environments (e.g., home, work or school settings) or the values or attitudes of others within these environments (e.g., family, friends, acquaintances, or strangers). Influences that may impact on the individual at the societal level include factors associated with the use of community services and organisations (e.g., government agencies; community activities; educational, health, housing, transport services and systems etc.) and include also formal and informal attitudes, regulations and service policies of these services. According to the ICF model, an individual's capacity to be involved in their chosen activities may be hindered by barriers within their environment (e.g., inaccessible buildings, lack of suitable services) or alternately, could be facilitated by features or services available in their environment (e.g., through the provision of assistive devices). Personal factors include characteristics of the individual, other than impairments or functional capacity, which may exert an influence on the individual's capacity to participate in activities. Included are factors such as age, gender, race, lifestyle, fitness, other health conditions, social and educational background, coping skills, and past and present experiences. Personal factors, although recognised as exerting an important influence on the functioning of the individual, are not classified within the ICF. As previously noted, disability is considered to be the result of the complex relationship between the individual's health condition and personal factors, as well as the external (environmental) factors that make up the situation in which the individual lives. Consequently, different environments are likely to impact differently on the individual with the health condition. Additionally, people with similar health conditions may have different experiences of disability due to the influence of different personal or environmental factors. (WHO, 2001).

This dynamic interaction between the person and their environment also underlies the AAIDD classification model (Luckasson et al., 2002). This model, called a *Supports Model*,

involves the application of targeted supports to reduce functional and activity limitations experienced by the individual, to enable achievement of desired personal outcomes. Fundamental to this model, and to the WHO model, is the view that disability is the manifestation of limitations in functioning within a social context. That is, the state of disability is not fixed but rather is changing as a function of the individual's limitations and available supports. Reducing the experience of disability results from the provision of interventions, services and/or supports (Luckasson et al., 2002). These conceptions of the state of disability and the themes underlying these models have a number of implications for the process of assessment of "typical performance". In particular, the following factors require consideration,

- the inclusion of external or environmental (e.g., physical access, assistive technology, attitudes) and/or other personal contextual factors (e.g., age, cultural background, previous experiences),
- the dynamic state of disability (e.g., due to changing nature of the contextual factors or stage of life of the person), and
- the inclusion of individual preferences and goals.

Both of these models of functioning challenge the notion of disability that underlies the assessment approach used in adaptive behaviour scales and requires us to redesign assessment practices (Luckasson et al., 2002).

4.2 Support Needs

One such response to this challenge to traditional assessment measures has been the development of the Support Intensity Scale (SIS; Thompson et al., 2004). The AAIDD developed the SIS following the introduction of the 1992 diagnostic and classification system, which was the first of the AAIDD classification manuals to introduce the Supports Model and include the concept of support intensities within the classification system. In the 1992

classification system, the use of IQ based categories (i.e., mild, moderate, severe, and profound) was dropped, and instead descriptions of needed support were incorporated for use by professionals to accompany diagnostic information. The four support intensity categories utilised were as follows:

- *Intermittent:* Supports on an "as needed basis," characterised by their episodic (person not always needing the support[s]) or short-term nature (supports needed during life - span transitions, e.g., job loss or acute medical crisis). Intermittent supports may be high or low intensity when provided.
- *Limited:* An intensity of supports characterised by consistency over time, time-limited but not of an intermittent nature, may require fewer staff members and less cost than more intense levels of support (e.g., time-limited employment training or transitional supports during the school-to-adult period).
- *Extensive:* Supports characterised by regular involvement (e.g., daily) in at least some environments (e.g., school, work, or home) and not time-limited nature (e.g., long-term support and long-term home living support).
- *Pervasive:* Supports characterised by their constancy, high intensity, provision across environments, potentially life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive or time-limited supports.

  (Luckasson et al., 2002, p. 152)

As is evident in these categories, the intensity of needed supports will vary over time (including life stages) and in different situations. Within this supports model, supports are considered to be the “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning.” (Luckasson et al., 2002, p. 15).

The inclusion in the 1992 AAIDD definition of intellectual disabilities of a supports intensity-based classification system was received with both favourable and unfavourable responses. In particular, the heightened focus on needed supports and the move away from a focus on deficits was favourably considered. Accompanying this paradigm shift, with its focus on supports, has been a move away from the use of segregated services, institutional settings, and professional control to one of community involvement, individualised supports and self-determination. This move has changed the support role from one of "care giving" to one of fostering support networks. Although not removing the role of paid caregivers, this approach requires a broadening of their roles beyond that of providing help with tasks such as those required for personal care (AAMR, 2003a).

Although the supports approach is conceptually attractive, concern has been expressed about the capacity to implement such a system due to a scarcity of accepted procedures for measuring support needs. Thus concerns have been raised that support needs, as with adaptive behaviour, were introduced without a substantial conceptual framework to guide the development and implementation of support needs instruments (MacMillan et al., 1993; Schalock , 2003). Thus, moving forward with such an approach requires an understanding of the concept of support needs, as well as the availability of reliable and valid measures for quantifying support needs.

4.2.1 Conceptualising and Defining Needs

Needs assessments are commonly used in a range of sectors, for example educational, business, health care and social sectors. They are used for the purpose of program or support planning and to allocate financial and service resources. Needs assessments have been the focus of research efforts within the disability sector, not only with regard to intellectual disabilities, but across a range of different disability categories including mental health. Yet, despite the broad application of such needs assessments, the concept of need remains

complex; and Mangen and Brewin (1991) considered that without clarity regarding what constitutes a need, processes designed to measure needs will likely be flawed.

Needs as a concept have been difficult to characterise, resulting in the development of a variety of approaches towards needs assessment, some of which have been haphazard with little theoretical or conceptual grounding (Baldwin, 1986; Issakidis & Teesson, 1999; Mangen & Brewin, 1991; Raghavan, Marshall, Lockwood, & Duggan, 2004; Royse & Drude, 1982). Whereas some approaches have involved the use of standardised instruments, others have used informal approaches to needs identification. Although not universally agreed (Marshall et al., 2004), there are some indications that needs may be overlooked with more informal approaches (Gallagher & Teesson, 2000; Raghavan et al., 2004; Slade, Phelan, & Thornicroft, 1998). This notion of needs being difficult to define is echoed by Thompson, McGrew, and Bruininks (2002) who described *support needs* as a "slippery construct" and suggested that a lack of clarity regarding the nature of this construct complicates the process of undertaking any reliable and systematic assessment of a person's support needs. Royse and Drude (1982) described need "as a term without conceptual boundaries and which requires an operational definition" (p. 99).

Two approaches can be used in order to conceptualise and define needs. One is a theoretical approach in which needs are understood in terms of models of human needs, motivation and drive. Such theories could include Maslow's *Hierarchy of* Needs (Maslow, 1970) which was first developed in 1943 and has evolved overtime from a five level model to a hierarchical model with nine levels of need, including:

1. *Physiological (Biological) Needs:* includes fundamental needs associated with basic survival such as food, water, excretion, sleep, exercise, and medical stability.

2. *Safety Needs*: includes needs associated with remaining free from physical or emotional harm incorporating personal safety within different settings (e.g., home, school, work, and community) as well as economic or financial security.
3. *Social or Affiliation (Belonging) Needs*: includes needs associated with having a sense of belonging and acceptance in small social associations (e.g., family, friends, and intimate relationships) or in larger social groups (e.g., social clubs, religious groups, and sports teams). This includes the need to give and receive love.
4. *Esteem Needs*: includes the need to be respected and to respect others, to have self-respect and esteem, to feel accepted and valued.
5. *Need to Know and Understand:* includes cognitive needs associated with learning, understanding and exploring.
6. *Aesthetic Needs:* includes the human need for beauty, to have something new or aesthetically pleasing.
7. *Need for Transcendence:* includes spiritual needs or "to be at one with the universe" (p. 242)
8. *Need for Freedom of Enquiry and Expression:* includes the need for an environment that permits free speech and that encourages fairness, justice and honesty.
9. *Self-Actualisation Needs*: This level is the highest level in Maslow's hierarchy and includes the need for people to make the most of their abilities and to endeavour to do their best and to work to fulfil their potential capacities and aptitudes.

(Huczynski & Buchanan, 2007)

In this model, the lower level needs (i.e., physiological, safety, social/affiliation and esteem needs) are described as "deficiency needs". Underlying this theory is the view that people are motivated to fulfil unmet or unsatisfied needs, and that the final stage of psychological growth (i.e., self-actualisation) only develops when needs at the lower levels of

the hierarchy have been met. It is the progression from one level of need to the next, described as a straight line continuum, which makes this model a one-dimensional hierarchy (Yang, 2003). Further, with this model the fulfilment of needs is considered to be healthy, whereas not meeting these lower needs can result in unpleasant feelings or consequences (i.e., anxiety, pain, discomfort).

As with contemporary models of functioning (e.g., the ICF), Maslow's model considers a person's state of functioning to be dynamic. Further, it incorporates an interaction between external factors and the person's capacity to function. Because Maslow's model assumes that higher levels of the hierarchy only become relevant when needs at the lower levels are fulfilled, then the model could be used to provide a framework for understanding the development of needs, in a similar way that it has been used to examine the development of quality of life (Hagerty, 1999). In terms of informing the process of needs assessment, the model could provide a guiding schema for the development of a needs assessment system, thereby ensuring comprehensive assessment of all salient deficiency needs, without neglecting the ultimate goal of ensuring the person reaches their maximum potential. Nosek and Fuhrer (1992) considered it an unfortunate reality for many individuals with very severe disabilities living in institutional settings that they have had needs at lower levels of the hierarchy addressed (i.e., they are clothed, fed, housed, and are kept safe from illness or injury), yet other aspects of their well-being have received little consideration, with few opportunities provided to enable higher order needs to be fulfilled. Whereas the application of resources directed towards needs at the lower physiological and safety levels of the hierarchy is very important for these individuals (e.g., to assist with eating, drinking, medication management, and to maintain health status etc.), it is also important to ensure that needs associated with higher levels of the hierarchy are addressed (e.g., social, esteem, and aesthetic needs). Failure of programs to consider the breadth of needs as outlined in Maslow's model is

highlighted by the number of instruments used in habilitation and rehabilitation settings that focus largely on cognitive and physical functioning, yet ignore other important issues such as environmental barriers and needs associated with achieving self-determination (Nosek & Fuhrer, 1992).

Maslow's Hierarchy of Needs has conceptual appeal and the appearance of face validity but various authors have questioned its empirical validity (Wahba & Bridwell, 1976; Yang, 2003). Some support has been found for the model or aspects of the model (Porat, 1977), although others report deficiencies with the model. In particular, inconsistent and sometimes contradictory findings have been reported regarding the nature and composition of the hierarchical model (Wahba & Bridwell, 1976; Yang, 2003). There has also been little evidence to support Maslow's assumption that higher order needs only arise when lower order needs have been satisfied (Yang, 2003). Additionally, Yang summarises numerous studies in which the cross cultural applicability of the model is found to be inadequate. The substantial review conducted by Wahba and Bridwell (1976) identified a number of issues of importance in relation to the theory that have relevance when considering the applicability of the model for defining need or for informing a process of needs assessment. In particular, they questioned the applicability of having a hierarchy to explain the structure of needs and queried whether the hierarchy would vary across people and over time. Further, they raised the following questions and concerns regarding the concept of needs included in this model and particularly, methods for measuring needs:

The most problematic aspect of Maslow's theory, however, is that dealing with the concept of need itself. It is not clear what is meant by the concept of need. Does need have a psychological and/or physiological base? Does a need come into existence because of a deficiency only or does need always exist even when it is gratified? How can we identify, isolate and measure different needs? (Wahba & Bridwell, 1976, p. 234).

Another model of need is that of Bradshaw (1977). Rather than specifying need domains along the lines of the Maslow model, this model of social need focuses on approaches for identifying and measuring needs. Bradshaw identified four types of need, two of which were external to the individual (normative and comparative need) and largely determined by "experts", whereas the other two related to the individual's perceptions (felt and expressed needs). In particular, the categories of need are:

1. *Normative need*: This refers to need that has been based on expert or professional opinion (e.g., government recommendations regarding immunisation schedules).
2. *Comparative need*: This is described as an inferred measure of need determined by identifying services provided in one area or to one group of a population and using this information to determine or infer need for services for others in a comparable group.
3. *Felt need*: This refers to what an individual or groups say or feel they need.
4. *Expressed need*: This type of need is sometimes referred to as demand and represents expression of felt needs.

(Baldwin, 1986; Royse & Drude, 1982)

Fundamental to this type of model of need are the notions of supply (i.e., what is provided) and demand (i.e., what people ask for or an expressed need). Extending on these concepts of supply and demand is the concept of needs either being met or unmet. This needs assessment approach involving the identification of met and unmet needs has been used in a suite of needs assessment instruments developed to assess the health and social needs of people with mental health problems. These assessments, called the Camberwell Assessment of Need, (Phelan et al., 1995; Slade, Loftus, Phelan, Thornicroft, Wykes, 1999) are used to guide support provision. Within these instruments needs are assessed across health domains (e.g., physical health, psychiatric symptoms, psychological distress etc.) and social domains

(e.g., accommodation, self-care, looking after the home etc.), using a scale in which these areas are assessed as being not a problem, a met need, or an unmet need.

Brewin, Wing, Mangen, Brugha and McCarthy (1987) have attempted to define the concepts of met and unmet need for the purpose of assessing need for care for individuals with mental health problems. They determined that a need is present when functioning falls below a specified minimum level and is due to a remediable (or potentially remediable) cause. Needs are considered to be met when some effective intervention has been implemented and when no better or more effective interventions are available. Unmet needs arise when no intervention, or only partly effective interventions have been applied and more effective interventions are considered to exist. They note that needs cannot be objectively determined but rather are based on a value system. Slade (1994) similarly describes need as "socially negotiated" (p. 294), warning that what may be considered a need by one person may not be recognised as a need by another. Research findings of discrepancies between staff and client ratings of need have led to suggestions that both sources should be consulted when undertaking a needs assessment (Issakidis & Teesson, 1999; Slade, 1994; Slade, Phelan, Thronicroft, & Parkman, 1996).

The other approach to defining needs is an empirical approach in which a comprehensive review of issues relevant to the construct under consideration, are analysed and categorised to form the basis of a measure used to assess the construct. It was this approach that was used by the AAIDD when developing a supports needs instrument named the Supports Intensity Scale (SIS). The SIS is a needs assessment instrument in which needs are defined and measured in terms of *need for supports*. Thompson, Hughes et al. (2002) conducted an extensive literature review and examination of existing assessments of adaptive behaviour, much like the early development process for the first AAMD adaptive behaviour scale, in an effort to determine the support categories for inclusion in a support needs

assessment system. Of the areas initially identified, four areas were not retained (personal care, technological, family, and financial) following implementation of a Q-sort procedure in which academic experts and practitioners were asked to rate the impact of particular items. The areas that were retained included:

1. Human Development Activities including:
    - ♦ Physical development (e.g., eye-hand coordination, fine motor skills, and gross motor skills)
    - ♦ Cognitive development (e.g., reasoning, coordinating sensory experiences)
    - ♦ Social-emotional development (e.g., trust, autonomy, initiative).
2. Life Long Learning Activities including self-determination, problem solving, functional academics, and physical education skills.
3. Home Living Activities including personal care tasks and operating home appliances.
4. Community Living Activities including using transportation, leisure, shopping, and interacting with community members.
5. Employment Activities including interacting with co-workers and supervisors, completing work related tasks, and learning job skills.
6. Health and Safety Activities including avoiding hazards, taking medications, maintaining physical health, and following rules and laws.
7. Behavioural Activities including maintaining socially appropriate behaviour, controlling anger and aggression, and learning skills and behaviours.
8. Social Activities including socialising, using appropriate social skills, and communicating needs.
9. Protection and Advocacy Activities including protecting self from exploitation, managing money and finances, and advocating for self and others.

   (Luckasson et al., 2002; Thompson, Hughes et al., 2002)

In addition to the areas listed above, two extra sections, critical medical and behavioural needs, were added because it was considered that they were significant contributors to need for supports. As can be seen there are similarities to the need areas of Maslow's model; for example, in the areas of home living, health and safety, social activities and protection and advocacy. However, of critical importance for the development of a practical support needs assessment system, the SIS model, unlike Maslow's model provides a means by which needs can be identified and measured. Thompson, Hughes et al. (2002) considered need for supports in terms of the pattern and intensity of supports that were required for the individual to participate in valued activities and settings. It was anticipated that across support areas, different intensities of support would be necessary with variations incorporating different amounts of support time, frequency with which support was required, and intrusiveness of the supports. These dimensions of support intensity are reflected in the support categories introduced by the AAIDD with the 1992 classification manual. The SIS has continued to change and evolve since this pilot version; however, this review served as the basis for conceptualising and operationalising the support needs concept (Luckasson et al., 2002; Schalock, 2004; Thompson, Hughes et al., 2002).

4.2.2 Relationship to Adaptive Behaviour and Models of Personal Competence

Like the adaptive behaviour scales addressed earlier, the Supports Intensity Scale (SIS) deals with typical performance in everyday activities although focusing on the supports required when participating in such activities. However, despite the fact that SIS and adaptive behaviours are dealing with similar types of daily living tasks and typical performance, the AAIDD considers adaptive behaviour and support needs to be related yet different constructs (AAMR, 2003b). In particular, adaptive behaviour scales focus on the skills required for effective functioning in society, whereas measures such as the SIS address the intensity of supports an individual would require to participate in the activities of everyday life. Further,

the AAIDD describes the major influences on need for supports as the presence of exceptional medical and/or exceptional behavioural support requirements and the number and complexity of settings and activities in which the person engages (AAMR, 2003b). The other major influence on need for supports is considered to be personal competence, which is measured using scales such as adaptive behaviour instruments and measures of IQ.

As with adaptive behaviour and support needs, personal competence and support needs are also considered to be related yet different constructs (AAMR, 2003b). Personal competence is considered to exert an influence over need for supports such that, the higher an individual's personal competence, then the less likely support is required to enable participation in the activities and settings of choice. Conversely, the lower an individual's personal competence then the more likely that person will require higher levels of support to enable participation in chosen activities or settings (Thompson, McGrew, & Bruininks, 2002). However, despite the influence exerted by personal competence over need for supports, Thompson (2003) noted that measures of personal competence, typically IQ and adaptive behaviour scales, are not considered to predict a person's support requirements adequately, because of limited assessment of physical and social competence and other identified influences on support.

Factors such as personal competence, as well as the presence of exceptional medical and behavioural needs, have been indicated as significant contributors towards support needs, yet little empirical research has been conducted to date to examine the impact of these factors. One such study that has examined factors that are predictors of support needs for individuals with intellectual disabilities was conducted in Australia by Riches (2003), using a recently developed scale called Supports: Classification and Assessment of Needs (SCAN). In this study, the number of support hours provided to clients in a 24 hour period was used as a basis for deriving four support need intensity categories (i.e., based on the AAIDD support intensity

categories of intermittent, limited, extensive, and pervasive supports) for use in analyses. Riches reported that adaptive behaviour (which included personal care, home living and community living skills), communication (which included ability to communicate choices, preferences, likes/dislikes, and to communicate with familiar and unfamiliar people), and physical care needs (which included assistance with mobility, lifting, transfers, bladder/bowel management) were significant predictors of support needs. Another domain examined included a medical and allied health domain. Three factors were identified in this domain: psychiatric disability, epilepsy, and other medical/health conditions. Riches reported that although this domain did not significantly predict overall support needs, it was a significant predictor of need for night support. Further, Riches suggested that the domain may serve to qualify the types of supports needed, and that the three medical/health factors may contribute towards need for supports in different ways.

Riches (2003) also reported that staff support hours were not associated with the presence of behaviour problems "in any predictable way" (p. 330), and concluded that while behaviour was also not a statistical predictor of general support needs, it appeared to act as an additional qualifier of the type and level of support needed. The SCAN also incorporated a risk profile score, which was established on the basis of whether there were any behaviours present that placed the person "at risk in some way" (p. 327). This profile was also found not to predict support needs. However, Riches reported that some individuals with low overall support needs were found to be in a high risk group whereas others with high support needs associated with coexisting physical disabilities were found to be less at risk and/or demonstrated fewer behavioural issues. This finding highlights the possibility, addressed in this thesis, that support needs are likely to vary across different domains in terms of the type and intensity of supports that may be required. That is, low support needs in one area will not necessarily mean low supports will be needed in all support domains. Consequently, to

provide an accurate assessment of support needs, an instrument should be multidimensional, with a scoring system that identifies needs at the domain level as well as providing an overall measure of need for supports.

4.2.3 Support Needs Assessments: Key Characteristics

Support needs instruments, as with adaptive behaviour instruments, are used for the purpose of determining support needs, assessing eligibility for services, prioritising applications, managing vacancies and, in some circumstances, to guide the allocation of funding resources (Riches, 2003; Thompson, Hughes et al., 2002). However, little has been published about how reliably and meaningfully these instruments estimate the support needs for the broad target group requiring or receiving support services. Instruments used for any purpose that may have a significant impact on an individual's life, such as determining eligibility for services and legal protections, or for the purposes of allocating financial resources, must be substantially reliable (Baldwin, 1986; Dyson, Allen, & Duckett, 2000; Guscia, Harries, Kirby, Nettelbeck, & Taplin, 2005; Thompson, Tassé, & McLaughlin, 2008). That is, the process requires that different caregivers would rate the same individual as having the same skills or need for support (Raghavan et al., 2004).

Various authors have identified criteria for adequate reliability for adaptive behaviour scales, including Cicchetti and Sparrow (1981) who considered reliability categories of poor (less than .40), fair (.40 to .59), good (.60 to .74) and excellent (.75 or greater). Others have recommended that scales used for the purposes of decision making should achieve much higher standards, setting the criterion at .90 (Aiken, 2000; Nunnally, 1967; Salvia & Ysseldyke, 1991), although Evans and Bradley-Johnson (1988) reported .85 to be a "satisfactory" benchmark. Consequently, psychometric standards for support needs measures that are to be used for decision making purposes, such as determining eligibility or for

funding allocation, will need to mirror the standards required for adaptive behaviour scales used for these purposes.

Adaptive behaviour and support needs instruments largely use a third party informant approach and require such assessors to indicate the degree to which skills can be performed in the person's typical environment. Reliance on this type of approach to assessment can mean a measure of reliability is sacrificed (Jenkinson, Sparrow, & Shinkfield, 1996; Spreat, 1982). Influential factors can include the severity of impairment, the nature of coexisting disabilities, age, and the familiarity of the informants with the individual being assessed, as well as the choice of informants (Evans & Bradley-Johnson, 1988). Various authors have reported discrepancies in assessments conducted using different informants (e.g., teachers and parents), and have suggested that the discrepancies arise due to different biases, value systems, and perceptions (Harrison, 1987, 1989; Meyers et al., 1979). Spreat (1999) cautioned that if variations between informants arise as behaviour varies across environments, then multiple assessments using multiple informants may be required to ensure reliable information is obtained.

The use of multiple informants has specifically been recommended when identifying need for supports (Riches, 2003; Thompson et al., 2004). Reliability or extent of agreement for maladaptive or challenging behaviours has generally been noted to be lower than for adaptive behaviour domains. Some have suggested that these differences may be associated with different informers providing ratings that differ due to personal value judgements. Thus, judgements associated with the perception of some of the frequency or severity of problem behaviours may differ from the value judgements of others (Dyson, Allen et al., 2000; Meyers et al., 1979). However, other authors have pointed out that these differences may indeed be real differences associated with different behavioural expressions in different environments or in the presence of particular respondents (McGill, Hughes, Teer, & Rye, 2001).

Support needs scales are likely to be subject to the same degree of variation and influences as adaptive behaviour scales because they also largely rely on third party approaches for collating information on needs and also look at the person's need for supports in their typical environment(s). Nonetheless, Thompson et al. (2008) cautioned that different interviewer skills and training may be required for administering a support needs assessment than are required for an adaptive behaviour assessment. They suggested that judgements about support, when using instruments such as the SIS, require numerous complex decisions to be made about multiple dimensions of support (i.e., frequency, type, and duration) for life activities across multiple personal competence domains. Frequently, these activities are complex (e.g., support required to make and keep friends or to engage in loving and intimate relationships) and determining the level of support an individual may need is not straightforward. Consequently, Thompson et al. suggested that more training was likely to be required for successful administration of a scale such as the SIS, than would be required for an adaptive behaviour scale. Their study found that reliability of the SIS was enhanced with interviewer training and/or experience with using the SIS.

Support needs scales are increasingly being used as instruments for establishing funding levels, with the overall objective of achieving equity of resource allocation. However, as previously indicated, this is not the only, nor even the major use of such instruments. Support needs instruments have also been developed to guide the development of individual support plans, with the objective of enhancing positive outcomes for individuals with disabilities. Adaptive behaviour scales were designed with similar aims. Spreat (1999) explains that a problem associated with the use of such instruments for multiple purposes is the dilemma of ensuring that the instruments include sufficient numbers of representative items. Instruments designed to measure multidimensional constructs (e.g., adaptive behaviour) must assess skills and behaviours across a number of domains. Yet, for

instruments to be used for the purpose of resource allocation, generally shorter instruments will be preferred, for obvious practical reasons. Nonetheless, for the purpose of developing an individual's support plan it is likely that a longer and more comprehensive measure of competency across multiple domains will be required. Thus, instruments useful for the purpose of support planning may be too long for the purpose of establishing eligibility for services or for diagnostic purposes. Therefore the challenge confronting scale developers is to establish instruments of a suitable length for the various purposes, whilst maintaining adequate coverage of multiple domains.

Multidimensional constructs such as adaptive behaviour are not straightforward to assess. Support needs, considered to be closely associated to adaptive behaviours, are likely to be equally complex to measure. A consideration when using measures of personal competence, such as adaptive behaviour, is the appropriateness of the instruments for individuals from different ethnic or socio-cultural backgrounds. Craig and Tassé (1999) reported that cultural differences associated with adaptive behaviour have been found, although they reported some confounding of findings associated with demographic variables (e.g., age, gender, socio-economic status), indicating that further research is required. In terms of administering an adaptive behaviour instrument, they suggested that considerable cross-cultural competence is required of interviewers to ensure valid assessment information is acquired. This means that interviewers need to be aware of the values and beliefs of different cultures as well as being able to communicate effectively with individuals from a linguistically diverse background (Tasse & Craig, 1999). As well, Craig and Tassé suggested that interviewers may be required to make judgements regarding skill deficits and determine whether the absence or lack of a skill is associated with a cultural difference (e.g., different expectations or opportunities to learn skills) or whether the deficit is associated with an underlying impairment. Similar clinical judgements and accommodations will likely be

required of interviewers when conducting support needs assessments with individuals from different cultural backgrounds. As with undertaking adaptive behaviour assessments, interviewers will need to be cognisant of language issues, different cultural expectations regarding skill competencies and developmental trajectories, cultural variations in attitudes towards individuals with disabilities (i.e., stigmatised in some societies), culturally appropriate support and interview approaches (e.g., sensitive to gender issues, eye contact), and previous experiences that may alter willingness to ask for, and accept assistance from services (e.g., suspicion of governments by immigrants or indigenous members of the community) (Craig & Tasse, 1999; DHS, 2003b; Saetermoe, Scattone, & Kim, 2001).

4.3 Implications for Support Needs Assessments

Support needs scales are relatively new approaches to the assessment of disability. The development and use of these types of scales have been driven by contemporary disability models in which the application of supports are considered necessary to ameliorate a person's experience of disability. This conceptualisation of disability has challenged existing assessment approaches in which the focus has been on identifying deficits, whereas now what is needed is to establish how to support the individual with a disability to enable them to participate more fully in the activities and settings of their choice. An extension of this approach to identifying need for supports has involved attempts to match the allocation of support funding to previously identified needs.

The advantages that are anticipated to result from the implementation of a support needs approach to funding services have previously been discussed. However, the success of such an approach relies on the extent to which we are able to identify "like clients" and implement a system that enables these clients to "be funded on a like basis" (Dyson, Duckett et al., 2000, p. 642). Moves towards needs based allocation of services or resources have been a significant impetus for the development of support needs assessments. This review of the

literature has identified several important implications with respect to the development or refinement of assessment instruments to be used for the purpose of identifying support needs.

1. Support Needs Conceptual Framework

The review of the literature has revealed that needs are complex. Attempts to define and understand needs include theories of needs such as the models proposed by Maslow (1970) and Bradshaw (1977). Bradshaw's model looked at needs in terms of whether they were determined by the individual (internal needs) or were externally determined (i.e., by experts), whereas Malsow's model considers that satisfying needs is fundamental to personal growth. Maslow's model identifies needs across multiple domains ranging from physiological to self-actualisation needs. Maslow suggested that individuals are not able to fulfil his or her potential (i.e., become self-actualised) if lower level needs are not met, but research has not supported this assumption. Nosek and Fufrer (1992) noted that, for many individuals with severe levels of disability, the support focus remains directed at needs at the lower physiological and safety levels, rather than addressing needs at higher levels, limiting the opportunities for these individuals to fulfil their full potential. In addition to highlighting the importance of considering needs across multiple domains, Maslow's model reinforces the importance of understanding the development of needs. By understanding the way in which needs develop, we are able to identify appropriate training and support priorities for individuals within a conceptual need framework. The approach utilised by Thompson, Hughes et al. (2002) to understanding needs for the purpose of identifying supports, involved a comprehensive review of existing instruments and consultation with experts. As with Maslow, they identified multiple need domains but extended beyond conceptualising needs to incorporate a method of measuring needs.

Human functioning is a complex phenomenon. Consequently, any assessment framework developed to guide the identification of needs, for the purpose of achieving

independent functioning, will also be complex. This is demonstrated in the frameworks proposed by Maslow and Thompson, Hughes et al., which revealed that it is necessary to consider needs across multiple dimensions of functioning and life activities. Another framework, that similarly provides a comprehensive view of the state of human functioning and disability, is the World Health Organisation's International Classification of Functioning, Disability, and Health (ICF). The ICF provides a comprehensive classification framework that includes three major components each of which is composed of multiple domains:

1. *Body Functions* (e.g., mental, sensory, voice and speech, cardiovascular etc.) *and Body Structures* (e.g., structures related to movement, speech, nervous system etc.);
2. *Activities and Participation Domains* (includes Learning and Applying Knowledge; General Tasks and Demands; Communication; Mobility; Self-Care; Domestic Life, Interpersonal Interactions and Relationships, Major Life Areas; Community, Social and Civic Life); and
3. *Contextual Factors* including *Environmental Factors* (includes Products and Technology; Natural Environment and Human-Made Changes to Environment; Support and Relationships; Attitudes; and Services, Systems and Policies) and *Personal Factors* (not classified in the ICF).

Frameworks such as those identified above provide useful conceptual frameworks for guiding the development of needs assessments systems or for evaluating the comprehensiveness of existing systems.

The Environmental factors identified in the ICF framework provide a comprehensive analysis of the factors that are also likely to impact on an individual's need for supports. Guscia, Ekberg et al. (2006) found little comprehensive assessment of the environment in instruments used within the disability sector. Contemporary models of functioning consider that an individual's experience of disability is a result of the interaction between the

individual (and their health condition or impairment) and the environmental factors that may either restrict or facilitate their participation in activities. Consequently, the identification of environmental factors, which may either be impeding independence (e.g., lack of adequate specialised transport or diminished carer capacity due to ill health or ageing), or factors that could be applied to facilitate independent functioning (e.g., appropriate assistive technology and devices), would contribute significantly to any assessment procedure developed to quantify need for supports and for implementing individual support plans. As found in the Chapter 2, environmental characteristics have been reported to be associated with cost of service provision. The inclusion of environmental factors in an instrument designed to quantify needs would assist with identifying the nature of supports that would be required to address particular environmental barriers, as well as providing information about "environmental" supports, which could in turn facilitate independent functioning (e.g., the purchase of assistive devices), for costing purposes.

The ICF also considers personal factors (e.g., age, gender, race, lifestyle, fitness, other health conditions, social and educational background, coping skills, and past and present experiences) as important influences on the functioning of an individual in different environments. Personal factors, other than an individual's impairments or health condition, which were identified in the Chapter 2, have been linked to cost of service provision. In particular, factors such as age, culture, the presence of changing or fluctuating conditions, were identified. Support needs instruments that incorporate indicators or measures of such personal factors would provide a useful source of information for qualifying the types and levels of supports that may be required. Riches (2003) reported on several factors that were found either to be qualifiers of types and levels of support required or predictors of need for supports. Included in these factors were the presence of behaviour problems and medical/health issues. Further, risk was identified as an important support consideration.

Personal risk factors (for example, personal vulnerability within the household or community settings), or legal issues are likely to have a significant impact on the type and level of support that an individual requires, making this an important area for inclusion in a support needs assessment. The SIS similarly incorporates assessment of personal factors, either as direct contributors towards the Support Need Index derived from the subscales (for example, the Health and Safety subscale), or in domains that are used to qualify types and levels of supports required (for example, the Exceptional Medical and Behavioural sections and the Protection and Advocacy supplementary scale). The available literature indicates that the identification and measurement of need for supports is complex and multidimensional, involving consideration of factors that are either direct contributors to, or qualifiers of, need for supports, across multiple life domains and settings.

2. Interviewer Training and Expertise

In addition to the complexity associated with identifying needs across a multiplicity of domains, Thompson et al. (2008) have noted that determining supports for many of the need areas in SIS is complicated by the nature of the life activities assessed. Often the areas are very personal or contextually specific and consequently supports are difficult to quantify. Familiarity with the instrument would facilitate the assessment process as would attendance at a training program designed to provide interviewers with skills required for facilitating such a needs assessment. Kirby et al. (2004) cautioned that although needs assessments appear simple and relatively straightforward and able to be completed by anyone familiar with the client, this is not always the case. Training in the use of support needs assessment instruments is recommended to ensure clarity with regard to the item content and to bring about consistency of the ratings provided and, hence, improved instrument reliability. In addition to ensuring that assessments are completed in a reliable and thorough manner, training programs would be able to focus on other relevant issues associated with the assessment process. For

example, in view of the complexity associated with conducting assessments with individuals from different cultural or ethnic backgrounds, training for interviewers could incorporate guidelines for conducting needs assessments in a culturally sensitive manner.

3. Choice of Informants

Identifying needs across multiple domains such as those included in the conceptual frameworks considered is a complex process. However, allocating funds on the basis of such needs assessments requires that the assessments be substantially reliable (Ridley & Jones, 2003). Indications within the literature note problems associated with the use of third party informant approaches. When using such approaches, behavioural differences have been reported in different settings and even in the presence of particular people like parents, teachers or paid caregivers. Additionally, discrepancies between staff/carer and client ratings of level of skill and needs have also been noted. Recommendations in the literature to overcome these difficulties include the use of multiple informants (Riches, 2003; Thompson et al., 2004), as well as including the client in the assessment process (Issakidis & Teesson, 1999; Slade, 1994; Slade et al., 1996). Slade (1996) considered that having clients or service users involved in the needs assessment process enabled a more effective prioritisation of needs, which was of benefit when resources are limited or rationed. One potential implication of the use of multiple informants is that the assessment process may be more time consuming and consequently more expensive to complete, particularly if the complex nature of the support needs assessment process requires the interviewer to possess at least tertiary level qualifications.

4. Breadth of Assessment

Instruments such as adaptive behaviour scales and support needs scales have been used for a multitude of purposes; for example, for fund allocation, for determining eligibility for services, for diagnostic purposes, and for the development of support plans. However, it is

unlikely that any one instrument could fulfil all of these purposes adequately. As previously discussed, instruments suitable for support planning are likely to be too long and unwieldy to be used for determining funding. As such it may be necessary for different instruments to be used for the different purposes, although as noted in the Chapter 2 it is important to ensure coherency between instruments used for funding and those used for support planning. A possible solution for scale developers is the development of multiple versions of instruments (e.g., short and long forms). Hatton et al. (2001) undertook to develop a short version of the Adaptive Behaviour Scale for research purposes. Although reporting encouraging findings, issues addressed included maintaining adequacy of the psychometric features and dimensionality of the instrument, as well as ensuring that in its short form the instrument was valid for all of the age ranges and cultural groups in the norming sample of the long form. Researchers undertaking to develop multiple versions of instruments would need to establish high degrees of coherence between the various instrument versions.

4.4 Implications for Future Research

This review of the literature has revealed human functioning for independence to be a complex phenomenon. As such, it is likely that the process of needs assessment to identify areas of support associated with deficits in areas of personal competence will also be complex. Moving forward with the development and use of needs assessment instruments will require broadening our understanding of the supports needs construct. In particular, it will be important to understand how it relates to the dimensions of personal competence and existing measures of adaptive behaviour, as well as understanding the manner in which other characteristics of the individual impact on both functional capacity and need for supports. These are areas that will be examined in the studies that follow.

SECTION C: Research Aims and Findings

Chapter 5: Research Aims

As detailed in the previous chapter, contemporary models of human functioning consider disability to be the result of the complex and dynamic interaction between the individual's health condition and personal factors, as well as these external (environmental) factors that make up the situation in which the individual lives that may either facilitate or hinder independent functioning. The American Association on Intellectual and Developmental Disabilities (AAIDD) similarly applies an ecological conceptual framework for understanding intellectual disabilities and advocates that the application of supports can facilitate functioning and thereby ameliorate the experience of disability that may arise for an individual in day to day life. The emphasis placed on the person-environment conceptualisations of disability, and the application of supports to enhance independent functioning, have been influential in the development of approaches to identify support needs. Further, this focus on the identification of an individual's need for supports has had applications in the funding of support services. Consequently, individualised needs based approaches are increasingly being utilised to fund support services for individuals with intellectual disabilities. The anticipated benefits of this approach have been well documented hitherto in Chapter 1.

Confronting the effective introduction of such an approach is the capacity to identify needs reliably and accurately. Needs based approaches are challenged by difficulties associated with defining and conceptualising needs. Theoretical models of human functioning, such as Greenspan' model of personal competence, the AAIDD's model of intellectual disability, and the World Health Organisations *International Classification of Functioning, Disability and Health* (ICF), demonstrate a multidimensional structure. Any

instrument designed to identify need for supports to address deficiencies in personal competence or functioning would be attempting to measure needs that are multidimensional. Further, needs are also likely to be dynamic as a consequence of the person-environment interaction considered to underlie a person's experience of disability. Yet, despite the conceptual appeal of identifying needs and funding supports on the basis of these needs, concern has been expressed about the absence of a substantial conceptual framework to guide the development and use of support needs measures. Thus, moving forward with such an approach requires an understanding of the concept of support needs. Three studies will be reported in this thesis that examine the nature of the support needs construct. In particular, these studies will look at the relationship between support needs and adaptive behaviours, in addition to examining the way in which the measures of adaptive behaviour and support needs are impacted by the presence of additional disabilities for individuals with a primary intellectual disability. These three studies have been reported in this thesis as chapters but constitute manuscripts prepared for journal publication. The first study has been published (i.e., Chapter 6 with a copy of the published proof provided in Appendix B), the second study has been accepted for publication (Chapter 7), and the third paper (Chapter 8) has been submitted for publication. Consequently, the chapter format reflects the layout required for journal manuscripts.

5.1 Research Aims for Study 1

The literature examined thus far has indicated that approaches used for establishing needs for the purpose of support funding have included the use of adaptive behaviour scales. Over the years adaptive behaviour instruments have been widely used and the construct extensively researched. Recent work has also addressed the positioning of adaptive behaviours within a model of personal competence. There is growing consensus of a multidimensional and possible hierarchical structure for adaptive behaviour. Multiple reviews

of factor analytic studies have pointed to the presence of four to five dimensions for adaptive behaviour. The AAIDD conceptual framework for adaptive behaviour includes three dimensions, (conceptual, social, and practical skills) consistent with proposed dimensions of personal competence.

The use of adaptive behaviour instruments to establish the need for supports for funding purposes involves an assumptive connection. That is, the greater an individual's deficits in terms of skills measured by adaptive behaviour scales (e.g., daily living skills, communication capacity etc.) the greater the need for support is assumed to be. On this basis, a close relationship between the concepts of adaptive behaviour and support needs is easily conceived. As previously reported, a recent cost study by Severance (2007) compared the predictive capacity of a supports measure, the Supports intensity Scale (SIS; Thompson et al., 2004) with that of an adaptive behaviour scale, the Inventory for Agency and Client Planning (ICAP; Bruininks et al., 1986). He found that the two measures had similar predictive capacity with regard to costs, providing support for the close relationship hypothesised to exist between the two constructs. Yet, as previously indicated, little has been reported concerning the nature of the relationship between support needs and adaptive behaviours, with little empirical analysis of the underlying structure of the support needs construct. Hence, the first study (Chapter 6: Support Needs and Adaptive Behaviours) endeavoured to investigate the nature of this relationship for individuals with intellectual disabilities.

Accordingly, a major aim of the first study was to examine this relationship using the six subscales that comprise the Support Need Scale of SIS and the subscales of two adaptive behaviour instruments, the Adaptive Behaviour Scale (ABS-RC:2; Nihira, Leland, & Lambert, 1993) and the ICAP. In particular, this study aimed to establish the extent to which SIS measured the same construct measured by the adaptive behaviour scales. Further, given the close theoretical relationship that has been hypothesised to exist between the constructs of

support and adaptive behaviour, a further aim of the study was to examine the extent to which the Support Need subscales of SIS measured the same dimensions conceptualised as constituting adaptive behaviour (i.e., conceptual, social, and practical skills) as measured by the ABS-RC:2 and the ICAP, or only some of the dimensions, or different dimensions.

5.2 Research Aims for Study 2

Assuming adaptive behaviours and support needs are closely related and measure dimensions of typical performance in everyday activities for individuals with intellectual disabilities, it would seem reasonable to expect that they would be similarly influenced by relevant characteristics of the individual. For instance, the presence of coexisting disabilities might be expected to impact similarly on functional capacity and consequent need for supports, albeit in a reciprocal fashion. An intuitive connection can be made between the presence of multiple disabilities, reduced functional capacity and the need for an individual to receive greater support. Consequently, this connection was examined in the second study (Chapter 7: Impact of the Number and Severity of Additional Disabilities on Adaptive Behaviour and Support Profiles for People with Intellectual Disabilities). The aim of this second study was firstly to investigate the incidence of multiple disabilities for a group of individuals with intellectual disabilities and secondly to examine the impact of the number and severity of these disabilities on adaptive and challenging behaviours and need for supports (including medical/health and behavioural needs), using one measure of adaptive behaviour (i.e., the ICAP) and two support needs measures, the SIS and the Service Need Assessment Profile (SNAP: Gould, 1998). Indicators of disability severity included the number of disabilities present, the severity of the primary disability and a cumulative measure of disability severity that incorporated the rated severity of each additional disability present. While informing the nature of the relationship between adaptive behaviours and support needs, understanding the impact of additional disabilities and the severity of these additional

disabilities on functional capacity and need for supports is likely to have important implications for service development and resource allocation, both in terms of the level of support funds required and the types and levels of caregiver expertise. Findings are discussed in terms of contemporary models of disability and support.

5.3 Research Aims for Study 3

While the number and severity of disabilities present are likely to be important in contributing to the extent of disability experienced by an individual, it also seems reasonable to expect that the nature of the additional disabilities present would be an important consideration. The literature reviewed in Chapter 2 revealed that the presence of particular additional disabilities was associated with higher costs for service provision (e.g., the presence of psychiatric, communication, or mobility disorders). The presence of a particular additional disability type is likely to be associated with unique patterns of skill deficits as measured using adaptive behaviour scales. For example, an individual with an intellectual disability and a coexisting physical disability is likely to demonstrate skill deficits in specific adaptive behaviour skill areas (e.g., motor skills). Given the expectation that support needs and adaptive behaviours are closely related constructs, it would be expected that instruments measuring need for supports would produce profiles that reflect underlying skill deficits identified using adaptive behaviour scales considered to be associated with the presence of particular additional disabilities. Coherence between the presence of particular skill deficits and need for supports in associated domains is explained by models of functioning such as the ICF and by the American Association on Intellectual and Developmental Disabilities (AAIDD) system of supports. The nature of this association was examined in the third study (Chapter 8: Impact of the Nature of Additional Disabilities on Adaptive Behaviour and Support Profiles for People with Intellectual Disabilities). Using the ICAP, SIS, and SNAP this study examined the impact of additional disabilities on adaptive behaviour skills and

support profiles to determine the extent to which the scales used produce profiles that reflected unique differences associated with the presence of particular disability types or additional impairments (including medical/health impairments and behavioural issues). Again, the findings are discussed in terms of contemporary models of disability and support and in terms of implications for the identification of support needs for the purpose of support planning and resource allocation.

5.4 Implications for Support Needs Assessment and Resource Allocation

As already identified, the nature of human functioning for independence is complex. Consequently, where deficits in areas of functioning exist, the identification and measurement of support needs to address these deficits are also likely to be complex. Getting the assessment process right will not be straightforward. Support needs scales are likely to require revision as our understanding of the construct evolves. It is anticipated that the literature reviewed and the findings of these three studies will provide information that can inform the development of support needs scales and/or the refinement of existing instruments.

Support Needs Assessment for Individuals with Intellectual Disabilities: An Investigation of the Nature of the Support Needs Construct and Disability Factors that Impact on Support Needs.

CHAPTER 6

SUPPORT NEEDS AND ADAPTIVE BEHAVIOURS

Julia Harries, Roma Guscia, Neil Kirby, Ted Nettelbeck, and John Taplin

School of Psychology,

University of Adelaide, Adelaide, SA. 5005 Australia

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STATEMENT OF AUTHORSHIP

SUPPORT NEEDS AND ADAPTIVE BEHAVIOURS

American Journal on Mental Retardation 2005, 110, 393-404.

HARRIES, JULIA (Candidate)

Collected data, performed analyses on data, interpreted data, wrote manuscript and acted as corresponding author

I hereby certify that the statement of contribution is accurate

Signed ……..Date.……

GUSCIA, ROMA

Assisted with data collection and manuscript evaluation

I hereby certify that the statement of contribution is accurate and I give permission for the inclusion of the paper in the thesis

Signed ……..Date.……

KIRBY, NEIL

Supervised development of work, helped in data interpretation and manuscript evaluation

I hereby certify that the statement of contribution is accurate and I give permission for the inclusion of the paper in the thesis

Signed ……..Date.……

NETTELBECK, TED

Undertook evaluation of the manuscript.

I hereby certify that the statement of contribution is accurate and I give permission for the inclusion of the paper in the thesis

Signed ……..Date.……

TAPLIN, JOHN

Supervised development of work

I hereby certify that the statement of contribution is accurate and I give permission for the inclusion of the paper in the thesis

Signed ……..Date.……

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Abstract

We used a prepublication version of the Supports Intensity Scale (SIS), the Adaptive Behavior Scale–Residential and Community, and the Inventory for Client and Agency Planning to examine the relationship between support needs and adaptive behavior for 80 people with intellectual disabilities. Dimensionality of the SIS Support Needs Scale (Section 1) was examined in reference to the three areas of conceptual, social, and practical skills reported by the American Association on Mental Retardation as comprising the adaptive behavior construct. Factor analysis of the adaptive behavior subscales and SIS Support Need Scale offered support for measurement of a common underlying construct. When considered in terms of the three adaptive behavior skill areas, this construct related predominantly to conceptual skills.

Support Needs Assessment for Individuals with Intellectual Disabilities: An Investigation of the Nature of the Support Needs Construct and Disability Factors that Impact on Support Needs.

CHAPTER 7

IMPACT OF THE NUMBER AND SEVERITY OF ADDITIONAL DISABILITIES ON ADAPTIVE BEHAVIOUR AND SUPPORT PROFILES FOR PEOPLE WITH INTELLECTUAL DISABILITIES.

Julia Harries, Roma Guscia, Ted Nettelbeck, and Neil Kirby

School of Psychology,

University of Adelaide, Adelaide, SA. 5005 Australia

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HARRIES, JULIA (Candidate)

Collected data, performed analyses on data, interpreted data, wrote manuscript and acted as corresponding author

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Signed ……..Date

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Abstract

Numerous researchers have reported a high incidence of additional disabilities coexisting with intellectual disabilities. Although an intuitive link can be made between the existence of multiple disabilities and greater need for support, little has been reported about this relationship. Using measures of adaptive functioning and support needs, we examined the extent to which adaptive and challenging behaviors and consequent support needs (including medical) were impacted by the presence and severity of additional disabilities for individuals with intellectual disabilities. Results show that adaptive behaviors and support needs were meaningfully related to the number and severity of additional disabilities present, whereas this was not so for challenging behaviors. Findings are discussed in terms of contemporary models of disability and functioning.

Support Needs Assessment for Individuals with Intellectual Disabilities: An Investigation of the Nature of the Support Needs Construct and Disability Factors that Impact on Support Needs.

CHAPTER 8

IMPACT OF THE NATURE OF ADDITIONAL DISABILITIES ON ADAPTIVE BEHAVIOUR AND SUPPORT PROFILES FOR PEOPLE WITH INTELLECTUAL DISABILITIES.

Julia Harries, Roma Guscia, Ted Nettelbeck, and Neil Kirby

School of Psychology,

University of Adelaide, Adelaide, SA. 5005 Australia

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HARRIES, JULIA (Candidate)

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SECTION D: General Discussion and Conclusions

Chapter 9: Support Needs Assessment for Individuals with Intellectual Disabilities: Understanding the Nature of the Support Needs Construct and Disability Factors that Impact on Need for Supports.

9.1 Overview: Project Context and Literature Summary

The research reported in this thesis has addressed issues associated with the assessment of support needs for individuals with a primary intellectual disability. Moreover, the thesis was designed to inform a larger research project directed towards the development of a model for understanding and determining the support needs of individuals with a range of different disability types, levels of severity, and combinations of disabilities. This project, a collaborative venture conducted in conjunction with the Office for Disability and Client Services (ODACS) of the South Australian Department for Families and Communities (DFC), addresses a challenge facing funding bodies worldwide and seeks to inform decisions regarding the distribution of support funding for individuals with disabilities in a manner that ensures equity, visibility and rationality.

Thus far, the arrangement by which disability support services in Australia have been funded has involved a traditional government to agency model, in which service providers have received funding based on broad criteria such as the numbers and profile of the disability group served, geographic location, model of service delivery, and past levels of funding received. As discussed in Chapter 1, with this model for funding the service providers are generally responsible for decisions regarding consumer access to services, the type and level of service provided, and the quality of service provided. An alternative approach to funding is an individualised or personalised funding approach. With this model, the allocation of funding is based on an individual's needs and funding commitments are made with the consumer, or person with a disability, rather than with service providers. Although not used widely in

Australia at present, the use of individualised approaches to fund allocation is increasing in line with the social justice principles guiding government policies of equal citizenship rights, equity and fairness of resource distribution, fair access to resources and services, and community participation and inclusion.

Dissatisfaction with the traditional model of funding allocation relates largely to equity and rationality. Both within Australia and overseas, funding inequities have developed as a result of such traditional funding approaches, with funding considered to be vulnerable, or at risk of change, as a result of advocacy or political pressures. As outlined in Chapter 1, lack of equity is a major concern for all stakeholders in the disability sector. Although individualised approaches to the funding of disability support services offer potential for reducing inequities through the use of needs based targeting of resources, the approach is by no means problem free. Various authors have identified important concerns needing attention when implementing such an individualised funding method, including service viability, accountability responsibilities and methods for establishing level of need (AIHW, 2002c; Butterworth, 2002; Dowson & Salisbury, 1999; Forbes, 2000; Laragy, 2002; Lord & Hutchinson, 2003). Of importance when implementing such an approach is the need to understand the types of consumer (service user) characteristics that are likely to impact on need for supports, and hence support costs, as well as understanding the extent to which current costs for service provision are driven by factors other than the level of need of the consumers (e.g., service characteristics).

Research into the factors that impact on the cost of service provision has, to a large extent, involved examining the cost of providing residential support services for individuals with intellectual and other developmental disabilities. Factors that have been investigated with regard to the association with costs have included both resident and service characteristics. What is evident from the literature reviewed in Chapter 2 is that varied findings have been

reported for both resident and service related characteristics. Moreover, similar variability has been reported in studies investigating the association between cost of service provision and service quality. Variability in costs and quality is reported to exist not only between different service types but also within the same types of services. The analysis of these relationships is not straightforward, with cost studies challenged by methodological and confounding factors; however, what does seem apparent is that underlying these relationships is a complex interaction of characteristics associated with the resident, facility and locality; a finding that has important implications for the development of needs based funding processes.

With respect to the research outlined in Chapter 2 into the relationship between resident needs and service costs or expenditures, results ranging from no association through to strong associations have been reported. What is also apparent from the literature is that not all sources of cost variation have yet been identified and some authors have suggested that there may be resident specific factors that impact on the cost of service provision, which are not adequately measured by the various instruments used in the cost studies. Additionally, there are indications within the literature discussed in Chapter 2 that it may be possible to enhance the strength of the association between individual characteristics and service costs through the use of individualised support and funding approaches rather than funding on the basis of service model types, through the use of continuous versus discrete funding level payment approaches, and where consistency exists between the approach used for deriving funding amounts and approach used for distributing funds.

The capacity to identify support needs adequately is crucial to the implementation of individualised approaches to funding of disability services for people with disabilities. Funding bodies use varied approaches in order to establish individualised budgets, but increasingly these approaches involve the use of standardised assessments. Frequently adaptive behaviour scales are used to establish these budgets although, more recently,

measures of support needs are being used for this purpose. Support need scales are more recent innovations, the development of which has largely been a response to contemporary models of functioning and disability. Within these models, disability is no longer simply explained by the presence of a particular impairment but is understood in terms of the interaction between the impairment and environmental barriers that restrict participation in everyday activities, as outlined in Chapter 4. This conceptualisation of disability has challenged existing assessment approaches, such as those using adaptive behaviour scales, in which the focus has been on identifying deficits, whereas now the focus is on the identification and application of supports to enable the person with a disability to participate in the activities and settings of their choice, thereby enhancing quality of life and personal well being.

The supports system, with use of support scales, on face value, offers an attractive alternative approach to measuring disability with its focus on the identification of supports to reduce the extent of disability experienced by the person. From a funding allocation perspective, this approach offers a mechanism by which the practical supports required by an individual can be identified and quantified, rather than extrapolating a level of need based on a deficit based measurement approach. Yet, as noted in Chapter 4, the move away from a deficit based approach to a supports based approach has not been greeted with universal enthusiasm. Concerns have been raised about the capacity to implement a support based classification system when few suitable measurement instruments exist for determining need for support.

9.2 Summary of Research Findings

In order to develop new instruments and to investigate the adequacy of the support needs scales currently in use, it is important that there be a suitable conceptual framework for understanding the support construct. The construct of support needs is still emerging and

requires investigation and clarification. Thus, an aim of Study 1 (Chapter 6: Support Needs and Adaptive Behaviours) was to investigate the nature of this construct, in addition to investigating the extent to which adaptive behaviour and support need instruments measure the same construct for individuals with intellectual disabilities. This relationship was investigated using the six Section 1 Support Needs subscales of the Supports Intensity Scale (SIS) and the adaptive behaviour subscales of the Adaptive Behaviour Scale–Residential and Community (ABS-RC:2), and the Inventory for Client and Agency Planning (ICAP). In view of the close theoretical relationship hypothesised to exist between the constructs of support and adaptive behaviour, the study also aimed to examine, using factor analysis procedures, the extent to which the Support Needs subscales of SIS measured the same dimensions conceptualised by the American Association on Intellectual and Developmental Disabilities (AAIDD) as constituting adaptive behaviour (i.e., conceptual, social, and practical skills) as measured by the ABS-RC:2 and the ICAP or, only some of the dimensions or whether it measured different dimensions.

Correlational findings of this study supported the notion of a close relationship between adaptive behaviours and support needs, and suggested some underlying commonality of measurement, albeit in a reciprocal fashion. All correlations between the adaptive behaviour measures and SIS Section 1 measures were significant and generally higher than had previously been reported by Thompson, Hughes et al. (2002). However, the findings of this study were consistent with those of Thompson, Hughes et al. with regard to the correlations between the SIS Section 1 measures and measures of challenging behaviour, which are mostly not significant. Sample characteristics (e.g., age, severity of intellectual impairment, presence of additional disabilities etc.) appeared not to be contributing to the findings of highly significant correlations.

Factor analysis was conducted to examine further the nature of the relationship, using the recommended approaches discussed in Chapter 3 (i.e., use of a factor extraction method, oblique rotations, and multiple approaches for determining the number of factors to be retained). Factor analysis of the SIS Section 1 subscales and the adaptive behaviour subscales, provided further indication that a close relationship existed between the constructs of adaptive behaviour and support needs. Further, the three factor solutions investigated did not identify any unique dimensions associated with the SIS Section 1 measures. Rather, the SIS Section 1 subscales appeared to be associated with the conceptual and, to a lesser extent, social dimensions of adaptive behaviour. Unexpectedly, an association with the practical dimension of adaptive behaviour was not found in this study.

In view of the apparent close relationship that seemed to exist between the constructs of adaptive behaviour and support needs, it did not seem unreasonable to expect that they would be similarly influenced by characteristics of the individual; in particular, the presence of coexisting disabilities. Initially the impact of the number and severity of additional disabilities present for individuals with intellectual disabilities was examined (Chapter 7: Impact of the Number and Severity of Additional Disabilities on Adaptive Behaviour and Support Profiles for People with Intellectual Disabilities). Three measures that have been used to guide fund allocation within disability support services were used to examine the impact of the coexisting disabilities; in particular, one adaptive behaviour measure (the ICAP) and two support need measures: the SIS and the Service Need Assessment Profile (SNAP). Consistent with the literature reviewed, the presence of coexisting disabilities was found to be an important issue for study participants with intellectual disabilities. Of the study sample, who were individuals receiving support from residential facilities in South Australia, 77% of participants had one or more coexisting disabilities, with the number of disabilities present significantly associated with increasing severity of intellectual impairment.

With regard to the impact of coexisting disabilities, adaptive behaviours and support needs (including need for medical/health supports) were found to be meaningfully related to the number and severity of disabilities present, whereas this was not so for challenging behaviours. Plotting mean scores and curve estimation statistics indicated fewer adaptive behaviours and a need for greater support (including medical/health supports) as number and severity of disabilities present increased, although the properties of these trends could not be established using curve estimation in this study. Graphing the profiles for challenging behaviours and need for behavioural support did not indicate a linear trend but instead revealed a number of directional changes associated with the number and severity of additional disabilities present. One possible explanation for this finding was that the profiles for the challenging behaviour measures obtained in this study were influenced more by the nature of the additional disabilities present than the number or severity of the disabilities.

Accordingly, the impact of the nature of additional disabilities present on adaptive and challenging behaviours, support and medical needs was subsequently investigated for individuals with intellectual disabilities (Chapter 8: Impact of the Nature of Additional Disabilities on Adaptive Behaviour and Support Profiles for People with Intellectual Disabilities). The same instruments utilised in Chapter 7 were used to undertake these investigations. Findings of the study indicated that each scale discriminated skills and needs associated with the presence of additional physical and speech disabilities. The support needs subscales of SNAP and SIS were more sensitive than the adaptive behaviour subscales of the ICAP to the needs of individuals with coexisting neurological and sensory disabilities. SNAP was the only instrument to identify unique needs associated with the presence of a psychiatric disability but SIS was the only instrument to discriminate needs associated with the presence of a vision disability. Based on the findings reported above regarding the apparent close relationship between adaptive behaviours and support needs, it was anticipated that the pattern

of results for the presence of particular coexisting disabilities as assessed by the two instrument types would reflect underlying deficiencies and produce coherent profiles. Yet, the results seemed to point to the support needs scales demonstrating greater sensitivity than the adaptive behaviour measure associated with unique characteristics of these coexisting conditions.

The findings of the three studies have provided valuable insights into the nature of the support needs construct, and particularly the relationship between support needs and adaptive behaviour. Further the findings, in conjunction with the literature reviewed, point to numerous important theoretical and practical implications associated with the process of conducting support needs assessments for individuals with intellectual disabilities. Additionally, they also raise issues for consideration associated with the development of new support needs instruments or the refinement of existing instruments to be used for the purpose of resource allocation.

9.3 Theoretical and Practical Implications

9.3.1 Relationship between Adaptive Behaviours and Support Needs

The findings of the first study supported the notion of commonality between the constructs of adaptive behaviour and support needs for individuals with intellectual disabilities. In particular, the single factor solution investigated produced a large factor, with loadings involving all SIS Section 1 subscales as well as all of the 14 adaptive behaviour subscales. Correlations obtained between the adaptive behaviour subscales and Section 1 subscales of SIS further supported this commonality, and were generally higher than those reported by Thompson, Hughes et al. (2002). Yet, these higher correlations have been further corroborated by the findings of a more recent study by Severance (2007), in which a correlation coefficient of -.74 was reported between the SIS Section 1 Index and the ICAP Broad Independence Index (an overall measure of adaptive behaviour). Severance also reported that costs of service provision were similarly predicted by this measure of adaptive

behaviour and the SIS. These findings offer further support for the supposition that the two instrument types are measuring a similar underlying construct and corroborate the existence of a close relationship between adaptive behaviours and support needs.

Further indication that the two instrument types measure a closely related underlying construct comes from the findings of the second study (Chapter 7). When examining the impact of the number and severity of disabilities on adaptive behaviours and support needs, correlations obtained were largely consistent and in the moderate to high range. The profiles presented in Figures 7.1a and 7.1b reflect similarities. Although not perfectly matched, these trends demonstrated that adaptive behaviours and support needs were similarly impacted by the number and severity of disabilities present, with a trend of fewer adaptive behaviours and a need for greater support associated with increasing number and severity of disabilities. With respect to the influence of the number of disabilities present on adaptive behaviours and support need measures, largely consistent findings were obtained from the Analysis of Variance with planned comparisons. The only difference of note involved the significant difference reported for the ICAP Service Score, for the mean comparison between individuals with three disabilities and those with four or more disabilities present. This finding may be associated with the fact that the computation of the ICAP Service Score incorporates both adaptive and challenging behaviours, suggesting that this result is consistent with the significant finding for this group comparison using the ICAP Generalised Maladaptive measure, but which was not found to be significant on the other two challenging behaviour measures considered here.

Adaptive behaviours and support needs seemed also to be similarly impacted by measures of disability severity. With regard to the results from the Analysis of Variance and planned comparisons investigating the impact of overall severity of disability, consistent findings were obtained between the ICAP Broad Independence Index and the overall measure

of needs using the ICAP and the SIS, whereas SNAP produced results that differed from the other instruments. This finding may have been related to scale composition, as suggested above for the finding regarding the ICAP Service Score. One of the main differences between the three instruments used in this research (SNAP, SIS and ICAP) involves the inclusion in SNAP of a measure of medical/health needs and behavioural support needs in an integrated total score. Although SIS does include separate scales for identifying these needs, they are not integrated within the final Support Need Index. ICAP includes a small number of questions on health and medical status, although the responses to these questions are not incorporated into a medical/health need score or in the calculation of any overall measure of adaptive behaviour or support (i.e., the Service Score); whereas challenging behaviours are assessed separately in the ICAP and are incorporated within the computation of the Service Score.

Similar consistencies between the ICAP Broad Independence Index and the overall measures of support needs derived from the ICAP and SIS were obtained when the nature of the additional disabilities present was examined (Chapter 8), with significantly fewer adaptive behaviours and greater need for support associated with the presence of coexisting physical disabilities or speech disabilities. Yet, again, the findings for the SNAP varied from those of the other two instruments, with the SNAP Day Support Hours total score indicating significantly greater need for supports associated with the presence of coexisting neurological disabilities. The nature of the scales that constitute the SNAP may be of importance in this finding as well as for those discussed previously, and particularly the medical/health focus of the SNAP.

Thus far, overall measures of adaptive behaviour and support needs have, by in large, been found to be similarly impacted by the number, severity and nature of coexisting disabilities, lending support to the idea that they are measuring closely related constructs. Yet at a subscale level, when the presence of particular coexisting disabilities was examined,

differences between the profiles obtained on the adaptive behaviour subscales and support need scales were evident. Although largely consistent findings of fewer adaptive skills and greater need for support were obtained at a subscale level for the presence of additional physical and speech disabilities, the support needs subscales investigated appeared to be sensitive to needs associated with the presence of coexisting neurological, sensory and psychiatric disabilities. These findings of significant differences associated with the presence of these additional disabilities were not highlighted by the ICAP adaptive behaviour measure, an instrument that was largely developed for individuals with intellectual and associated developmental disabilities. The findings of this study, and that reported above, appeared to indicate commonality of measurement at a broader overall level for adaptive behaviour and support needs using the scales employed in this research, but suggested that at a subscale level, unique measurement differences between the two instrument types can exist.

Correspondence found between adaptive behaviour and support needs, and particularly the manner in which each was similarly impacted by the number and severity of coexisting disabilities present, has been discussed in Chapter 7 in terms of contemporary models of functioning and disability. Specifically, models such as the World Health Organisations International Classification of Functioning, Disability and Health or the ICF, as well as in terms of models of functioning associated with ageing as suggested by Lawton and Nahemow's (1973) Ecological Model of Aging (EMA), have been examined. In each of these models an individual's health and wellbeing are considered to be a function of the balance or interaction between personal competence and environmental demands. The Ecological Model of Ageing proposes that, for each level of competence, there are different ranges of environmental demands at which an individual is able to function. Those with high personal competence are considered to have a broader scope for interacting and adapting to their environment, in ways that maximise positive outcomes and opportunities for participation in

life activities, while those less competent are more vulnerable to the demands of the environment and consequently require higher levels of environmental support. The application of supports to lessen the discrepancy between the person's capacity and the environmental demands, and to ameliorate the experience of disability, underpins the American Association on Intellectual and Developmental Disabilities (AAIDD) System of Supports Classification (Luckasson et al, 2002), which served as the conceptual basis for the development of the SIS. In terms of the current research, functional capacity (measured using an adaptive behaviour scale) was found to decrease as number of disabilities and severity of additional disabilities increased, while overall support needs were greater. This reduced functional capacity would be considered to lessen the individual's threshold for coping with environmental demands, thereby necessitating the introduction of supports aimed at improving individual functioning, hence the reciprocal association obtained for the overall measures of adaptive behaviour and support needs.

This person-environment interaction may be significant in the findings of differences at the subscale level associated with the presence of particular coexisting disabilities reported on the support needs subscales but not identified using the adaptive behaviour subscales. Unique differences associated with the presence of particular coexisting disabilities are to be expected on the basis of these interaction models. As discussed in Chapter 8, the presence of a particular impairment is likely to result in unique skill deficits and the consequent need for support in very specific areas. Although adaptive skill profiles should reflect the unique nature of deficits associated with the presence of particular coexisting disabilities, the subscales from the ICAP appeared not to be as sensitive to these unique characteristics as were the support need subscales in this research. This sensitivity possibly reflects the assessment approach inherent in support need measures, for which one is required to consider the need for support in terms of the interaction between the person's skills and capacity and

the environmental demands associated with performing various daily life activities in a variety of settings.

The close relationship between adaptive behaviours and support needs, as indicated in the work of Severance (2007) and confirmed here, has implications for the use of the two instrument types for the purpose of resource allocation. Specifically, it points to the possible use of the two types of scales interchangeably in order to meet a desired assessment purpose. For example, adaptive behaviour scales, which are objective and auditable, could be used for measurement of need for fund allocation, thereby addressing the recognised problem of greater gaming or rater bias inherent in the more subjective assessment of support needs (Kirby, 2006). Subsequently, support needs instruments could be used to guide the distribution of support funds to meet identified needs, by highlighting actual support requirements and potential sources of supports. However, for this type of arrangement to work successfully, it would be important to ensure consistency between the measures or procedures used to determine funding and the measures or procedures used for establishing each individual's program and support requirements, in order to achieve coherence between the level of support needed for an individual and the funds allocated for this support.

Alternately, given the close relationship found to be present between adaptive behaviour and support needs measures, it may be possible to use the two instruments in a cooperative fashion in order to refine decisions associated with resource allocation. This may occur either when the level of funding derived using a support needs measure is disputed or results in the individual falling on the cusp of a funding band level. The use of an adaptive behaviour scale in these circumstances may contribute valuable information to guide decisions regarding funding. In support of this suggestion is the finding by Severance (2007) that combining the ICAP and SIS marginally improved the capacity to predict costs in day and residential services.

9.3.2 Support Needs: Composition and Key Assessment Issues

The finding of a possible large single factor with loadings on all SIS Section 1 subscales and all adaptive behaviour subscales has corroborated the notion that the two instruments measure the same underlying construct; yet, when considering the impact of the nature of coexisting disabilities on adaptive behaviours and need for support, slightly different profiles were evident for measures of adaptive behaviour and support needs. This therefore raised the possibility that there were underlying differences between the constructs. Thus, further factor analysis was conducted to investigate possible alternate factor solutions and to investigate the dimensionality of the SIS in terms of correspondence to the three areas of conceptual, social and practical skills considered as comprising the construct of adaptive behaviour (Chapter 6). An interesting finding from these analyses, obtained for both the two and three factor solutions, was the loading of all SIS subscales on the dimension considered to be measuring conceptual skills. Further, neither the two nor the three factor solutions indicated any support for the possibility that SIS Section 1 subscales were measuring any dimensions distinct to those considered to be underlying adaptive behaviour. Indeed, in some circumstances where some correspondence between the subscales and the underlying dimensions might be expected, no such association was obtained. For example, the SIS Home Living subscale addresses supports required for activities of daily living (e.g., eating, toileting, dressing, etc) and instrumental activities of daily living (e.g., meal preparation, housekeeping use, etc), which are considered to be activities associated with competence in the practical skill dimension of adaptive behaviour; yet the SIS Home Living did not load on the factor that seemed to be measuring this practical dimension in the three factor solution, whereas three adaptive behaviour subscales did (i.e., the ABS Physical Development subscale, and the ICAP Motor Skills and Personal Living Skills subscales).

Findings of the correlational analyses reported in Chapter 6 further supported the importance of the conceptual dimension. In general, higher correlation coefficients were obtained for the SIS Section 1 subscales and SIS Section 1 Total Score with the Community Self-Sufficiency factor of the ABS-RC:2, which is considered to represent the Conceptual Skills adaptive behaviour dimension. Exceptions, however, included the SIS Home Living subscale, which correlated highest with the ICAP Personal Living subscale; and the SIS Social Activity subscale, which had equally high correlations with the ICAP Personal Living subscale and Service Score, the ABS Personal-Social Responsibility factor, as well as the Community Self-Sufficiency factor. Consequently, it was suggested that the caregivers involved in this study may have used each individual's conceptual competence as a frame of reference when attempting to assess support needs.

This finding has some correspondence to adaptive behaviour research that has involved examining correlations between measures of intelligence and adaptive behaviours. In particular, higher correlations between intelligence and adaptive behaviour have been reported when the adaptive behaviour scales have been completed using a teacher as the third party informant than when a parent acts as the informant (Harrison, 1989). Although not proven, one suggestion offered is that the teachers may not always be familiar with an individual's competency across all items in the adaptive behaviour scale. Consequently, to rate items that have not been observed, the teachers are required to make a "best guess" or judgement, and in doing this, the guesses are frequently based on knowledge of the individual's cognitive functioning. In the first study here (Chapter 6), all informants were caregivers who had worked closely with the participants for at least three months. Although they were likely to have observed the individuals in a number of different settings, it is probable that they had not provided support to all participants in the breadth of areas assessed in the SIS. Consequently, it is possible that, when required to rate support needs in unfamiliar areas, they made a guess

or judgement based on cognitive (or conceptual) skills. This may account for the pattern of generally higher coefficients obtained for SIS subscales and total score with the Community Self-Sufficiency factor. This matter has implications with respect to the training requirements for using support needs scales, for example training of interviewers in how best to elicit and clarify the types and intensity of supports an individual may require across a broad range of life domains as well as knowing when to source assessment information from other possible informants.

In a recent a re-analysis of the inter-rater reliability of the SIS, Thompson et al. (2008) emphasised the importance of training and familiarity for interviewers conducting assessment using the SIS, due to the complex nature of the support areas addressed and the complex nature of the judgements that are required. This issue of familiarity may be an important consideration when interpreting the findings of the study reported in Chapter 6. On the one hand, some of the support areas assessed in SIS would be very familiar areas for residential caregivers to judge the intensity of supports needed. For example, the SIS Home Living subscale assesses intensity of supports required for daily living tasks or instrumental tasks of daily living, with which most residential caregivers would likely be very familiar. The high correlations between the SIS Home Living subscale and the ICAP Personal Living subscale possibly support this familiarity. On the other hand, other areas assessed in the SIS would not be so familiar, and may include areas not previously considered by the caregivers, causing them to rely on their best judgement. Many of these needs are likely to relate to the higher order needs as described by Maslow's model. For example, *"Engaging in loving and intimate relationships"* as assessed in the SIS Social Activities subscale would fall within the Social/Affiliation (Belonging) Needs level, and may present as more challenging for caregivers to assess than would an adaptive behaviour item similarly directed. That is, caregivers may find it more straightforward to rate whether someone has the skills to

undertake such a life activity independently than to rate the type and intensity of supports that would be required to ensure an individual was successful and independent in such a life area. As already noted, despite the complexity involved in determining the type and intensity of supports required across a multitude of personal competence domains, it is nonetheless important that such higher order needs be considered in a needs assessment system, rather than simply focusing on the supports required for the lower level physiological and safety needs.

The issue of familiarity may explain the finding of lower correlations between all adaptive behaviour subscales and factor scores with the SIS Employment Activities subscale reported in Chapter 6. Although this finding may be in some way associated with the inadequate assessment of the vocational skills in many adaptive behaviour scales, as reported by Widaman and McGrew (1996), it may also relate to the familiarity of the caregivers with supports needed in an employment environment. As previously noted, all informants in this study were residential caregivers. Consequently, they may have lacked adequate knowledge of the type and intensity of supports needed by the study's participants at work. The use of more than one informant was not feasible in this research study, but is recommended in situations where the information is being gathered to inform decisions associated with the costing and provision of supports for individuals. The use of multiple informants (e.g., client, caregivers in home and leisure settings, work supervisors etc.) is likely to enhance the reliability of the information obtained and is recommended by support needs scale developers (Riches, 2003; Thompson et al., 2004), as is involving the individual in the process of identifying and prioritising needs wherever practical (Issakidis & Teesson, 1999; Slade, 1994; Slade et al., 1996).

Choice of informants for involvement in the need assessment process is an important consideration when undertaking a needs assessment. The issues raised above highlight the fact

that it is difficult for one person to know all there is to know about another person's need for support, particularly given the broad range of life domains that must be considered and the heterogeneous nature of intellectual disabilities. This research has demonstrated the extent of multiple disabilities associated with intellectual disability. Further, although a significant proportion of study participants had more than one disability, the literature reveals that the information obtained regarding the presence of coexisting disabilities using caregiver reports is likely to underestimate the actual number of coexisting impairments present (Kerr et al., 2003). Communication problems are considered to be an important factor in these underestimates.

Similarly, the literature suggests that communication issues are also significant in the underreporting of health conditions. Thus, limited communication skills restrict capacity to communicate pain or discomfort and verbalise symptoms. Yet, the literature indicates that health conditions are more prevalent for individuals with intellectual disabilities (Beange, Lennox, & Parmenter, 1999). Additionally, the current research (Chapter 8) has demonstrated that the need for medical/health supports was significantly greater for those individuals with intellectual disabilities who also had coexisting physical, neurological or speech disabilities than when these coexisting disabilities were not present. Moreover, in Chapter 7 the need for medical/health supports was found to increase significantly as the number and severity of disabilities increased. Various authors have noted that the presence of medical/health conditions are a predictor of higher service provision costs (Campbell et al., 2005; Lakin et al., 2005; Stancliffe, 2005; Thompson et al., 2004), whereas Riches (2003) reported that these needs were a significant predictor of need for night support. Consequently, the identification of medical/health needs is an important requirement for a needs assessment system.

As indicated in earlier chapters, the use of support needs instruments to guide the allocation of government funds is a recent innovation. One of the anticipated benefits of the

support needs approach is the capacity to identify unique needs in a diverse population of support recipients, by considering the interaction between the person's skills and capacities with the environmental demands present when undertaking daily life activities in a range of different settings. The extent to which the instruments are able to produce unique profiles that reflect the variety of needs associated with the presence of an intellectual disability, and possible additional disabilities, is likely to serve as an indicator of their utility as funding tools. It is apparent from the literature reviewed and from the findings of the current research, that the assessment of support needs must be multidimensional in order to address the multiple life domains in which an individual may require supports, as well as addressing the heterogeneous nature of disability. As reported above, the need for supports directed towards medical/health issues was found to be significant for individuals with three coexisting disability types. In Chapter 8, further differences associated with the presence of particular disabilities were reported. For example, the presence of a coexisting sensory disability was associated with significantly higher needs in the areas of Life-Long Learning and Night Support; significantly higher needs in the areas of Community Living, Life-Long Learning and Protection and Advocacy were obtained in the presence of a coexisting vision disability; significantly higher need for Behavioural Support in the presence of a coexisting psychiatric disability was contrasted with significantly lower needs in this area for individuals with coexisting physical disabilities. In order to address these unique differences it is apparent that a supports needs system must be based on a comprehensive guiding framework.

One such framework is that outlined in the ICF. The ICF provides a comprehensive coverage of domains associated with participation in life activities (e.g., Communication, Mobility, Self-Care, Domestic Life, etc). In addition, it provides a thorough Body Structures and Functions framework, which can be used for developing protocols for the identification of health and other impairments as well as associated needs for medical/health support. In

keeping with the underlying conceptual model of functioning of the ICF (the person-environment interaction model), the ICF also includes a comprehensive framework for identifying environmental facilitators and barriers. Although this interactive approach towards disability is widely accepted, few assessment instruments include comprehensive coverage of this important area. Guscia, Ekberg et al. (2006) have recommended the ICF classification of environmental factors as a resource for evaluating the environmental content of existing instruments, and for the revision of existing instruments or for the development of future assessment instruments.

The problem facing scale developers though is how to incorporate all of the necessary dimensions of support without the instrument becoming unwieldy or impacting the utility of the instrument, particularly in view of the heterogeneous nature of disability associated with the presence of coexisting disabilities. In addition to having adequate reliability and validity, instruments need also to demonstrate good feasibility (Andrews, Peters, & Teeson, 1994). Andrews et al. have described feasibility as incorporating three elements: applicability (i.e., the extent to which the instrument is applicable for all potential users); acceptability (i.e., the user-friendliness of the instrument); and practicality (i.e., the extent to which the instrument can be utilised, including issues associated with cost, need for user training, and interpretation of results). The literature reviewed also highlighted the importance of coherence between measures used to establish a funding level and measures used to guide support planning. One suggested approach to ensure coherence between measures used for funding and those used for support planning, is to develop short forms of an instrument, thereby maintaining consistency between domains assessed for funding and for support provision, while improving the feasibility of the instrument.

Yet, scale developers need to be cautious when attempting to develop a brief funding instrument that has good feasibility (i.e., good user-acceptance, not too costly or time

consuming to implement, etc.), that they do not ignore important personal characteristics likely to impact on need for support as well as assessment features important for enhancing quality of life. Personal factors may include particular or unique characteristics of the person, for example, the person's cultural or linguistic background, the presence of needs that may be fluctuating or changing, as well as the person's aspirations. Important needs may arise due to personal risk factors; for example, this research identified the importance of supports in the area of protection and advocacy (e.g., protecting self from exploitation, advocating for self, making choices or decisions, etc.) for individuals with an intellectual disability and coexisting vision or speech disabilities.

The literature reviewed has highlighted the importance of addressing needs other than basic physiological or safety needs. Training needs were also identified as important. The close association between adaptive behaviours and support needs reported in this research highlights the fact that, in progressing an individual's level of adaptive behaviours, consequent reductions in level of support needed should follow, thereby freeing up resources for other clients in need. In addition, the literature reviewed in Chapter 2 has indicated the association between greater levels of adaptive behaviours and better quality of life outcomes, leading to the proposition that the identification and application of training supports directed towards the development of adaptive behaviours will bring about improved quality of life for individuals with intellectual and associated developmental disabilities.

9.3.3 Relationship between Challenging Behaviours and Support Needs

Although the correlations obtained between adaptive behaviours and support needs reported in Chapter 6 were generally higher than those reported by Thompson, Hughes et al. (2002), consistent findings were obtained for the challenging behaviour measures. Weak and largely non-significant findings were obtained between the SIS Section 1 subscales and SIS Section 1 Total score and the challenging behaviour measures (i.e., ICAP maladaptive indices

and the ABS-RC:2 maladaptive factor scores), indicating that the need for support in the SIS Section 1 subscales was largely unrelated to the presence of challenging behaviour problems. These results reflect the low relationship reported in the literature between adaptive behaviour and challenging behaviour, which is considered to corroborate the idea that adaptive and maladaptive behaviours are separate and discrete constructs. Yet, as reported in Chapter 3 some adaptive behaviour factor studies have found overlap between the two constructs (i.e., adaptive behaviour factors with positive loadings for the adaptive variables and negative loadings for the maladaptive behaviour variables or maladaptive behaviour factors with negative loadings for the adaptive variables and positive loadings for the maladaptive behaviour variables). For example, Lambert and Nicoll (1976) reported negative loadings for two maladaptive behaviour variables (i.e., called Withdrawn and Untrustworthy) associated with a factor termed Social Responsibility, which had positive loadings for three adaptive behaviour variables (i.e., Self-Direction, Responsibility, and Socialisation), indicating some overlap between the two constructs of adaptive and maladaptive behaviours, associated with the complementary nature of the association with the dimension under consideration That is, an individual scoring highly in the area of social responsibility, is unlikely to score highly in terms of being withdrawn or untrustworthy.

As discussed in Chapter 3, Roszkowski et al. (1983) used canonical correlations to examine the overlap between adaptive and maladaptive behaviours, using the Adaptive Behaviour Scale (ABS). They reported a similar overlap associated with sociability, finding positive loadings on Socialisation and Self-Direction were associated with negative loadings on Withdrawal. In terms of need for support, it is perhaps also not unreasonable to expect some overlap between the presence of challenging behaviours and need for additional support in some of the life domains measured in the SIS Section 1 subscales, such as discussed above for adaptive behaviours. For example, the ICAP assesses internalised maladaptive behaviours

(i.e., incorporating behaviours such as hurtful to self, unusual or repetitive habits, or withdrawal or inattentive behaviours), and the ABS-RC:2 assesses Personal Adjustment problems (i.e., incorporating problem sexual behaviours, self-abusive behaviour, and social engagement problems). The likelihood exists that the presence of these behaviours would impact on need for support in a number of the life areas addressed in the SIS, particularly areas that incorporate support needs associated with socialising, interacting with others (e.g., co-workers, supervisors, peers, community members etc), and engaging in activities (e.g., leisure/recreation, volunteer work, community activities etc.). An association between the presence of these internalised/personal adjustment problems and need for support in the Social Activities subscale would perhaps reflect this overlap.

In the first study reported here (Chapter 6), two weak but statistically significant correlations were obtained between measures of challenging behaviour and SIS Section 1 subscales, although only one made logical sense or was consistent with the findings of Roszkowski et al. (1983) or those of Lambert and Nicoll (1976) reported above. That is, an association (r =-.22) was obtained between the need for more support in Social Activities and the presence of internalised maladaptive behaviours as established using the ICAP. The second correlation (r=-.24) involved the need for more support in the area of Life Long Learning and the presence of fewer Social Adjustment problem behaviours (i.e., as assessed on the ABS-RC:2 including behaviours such as social behaviour problems including threatening behaviours, temper tantrums, teasing, disrupting others, etc; conformity behaviour problems such as ignoring rules, absconding, resists instructions, etc; and problems associated with trustworthiness such as telling lies, damaging property, stealing, etc). An examination of scatter plots (not reported in the chapter) revealed that the associations were indeed weak, with a large spread of scores present in the data. More detailed discussion of the findings with respect to the association between challenging behaviours and need for supports was not

discussed in the chapter because of the very weak nature of the correlation, but the findings are discussed here as part of a more comprehensive account of the results and to provide possible directions for future research.

The other dimensions reported by Roszkowski et al. (1983) as accounting for overlap between adaptive and maladaptive behaviours were intellectual ability and physical ability. In the research discussed in Chapter 7, severity of intellectual impairment was found to be moderately associated with scores obtained on adaptive behaviour measures, with similar moderate to high correlations obtained between level of intellectual impairment and measures of support. However, there was little evidence of any association between intellectual ability and challenging (maladaptive) behaviours. Although a weak association was obtained between the presence of fewer challenging behaviours as measured on the ICAP and increasing severity of intellectual impairment, no association was obtained between severity of intellectual impairment and need for behavioural supports. Yet, an association (inverse) was obtained between the need for behavioural support and the presence of a physical disability, similar to the findings reported by Roszkowski et al. In particular, the need for behavioural supports was found to be significantly lower in the presence of a coexisting physical disability, with this research also finding significantly higher need for behavioural support associated with the presence of a psychiatric disability. While these findings provide some insight into the impact of behaviour problems on need for support, it is apparent that further clarification is required.

There are a number of factors that could be addressed in future studies in an attempt to understand the impact of challenging behaviours on need for supports. In particular, factors such as age, level of intellectual disability severity, the nature of coexisting disabilities, or possible interactions between coexisting disabilities, may provide useful insights into the impact of challenging behaviours on need for support. Challenging behaviours may be more

prominent at particular times or in particular circumstances. For example, challenging behaviours may be associated with the presence of a new medical condition, ageing (e.g., dementia), or a fluctuating psychiatric condition, possibly confounding findings associated with challenging behaviours and need for supports. Furthermore, it may be that challenging behaviours are more susceptible to contextual issues than are other needs. For example, need for medical/health or personal care supports may be more likely to remain consistent across environments or settings than would behavioural supports. As reported in Chapter 4, the presence and severity of challenging behaviours have been reported to vary according to the setting or the presence of particular individuals, suggesting supports are likely to vary accordingly.

Findings in the literature further support the need for clarification regarding the association between need for support and the presence of challenging behaviours. Perhaps unexpectedly, Riches (2003) reported that maladaptive behaviour was not a predictor of supports received (i.e., support hours received) and concluded that behaviour was possibly a qualifier of the types and levels of supports likely to be required. However, some studies have reported that the presence of challenging behaviours does predict costs of service provision (Campbell et al., 2005; Emerson et al., 2005; Felce et al., 2003), whereas others have not (Rhoades & Altman, 2001; Stancliffe, 2005: Stancliffe & Lakin, 1998). Kastner and Walsh (2008) have described challenging behaviours associated with intellectual disabilities as "multifactorial, often arising from unmet health care, psychiatric, and/or environmental factors" (p. 241). The inclusion of measures of need for behavioural support in support needs measures such as SIS and SNAP indicates the presumed importance of behaviour, yet the manner in which it impacts support needs is not yet clear and warrants further investigation.

9.4 Limitations of the Studies and Implications for Future Research

The findings reported in this research need to be considered in terms of methodological limitations and associated impacts of these limitations on the study findings. The limitations for each study have been outlined in detail in each chapter, along with the associated impacts and any suggested future research. Notwithstanding these limitations, the research findings contribute to the understanding of the construct of support and the process of need identification, as well as identifying avenues for future research.

A limitation reported in each of the three studies related to the representativeness of the study group. In particular, all study participants were in receipt of residential support services and lived in a range of supported accommodation options, ranging from group homes to larger institutional settings. As has been previously indicated, data from the AIHW (2007) indicates that accommodation support recipients with intellectual disabilities have a higher incidence of multiple disabilities than when all funded support services are considered. Nonetheless, as noted in Chapter 7, a large proportion of the funds allocated by the Australian government for disability services is directed towards the provision of accommodation supports (accounting for about half of total expenditure), indicating that, although the study group may not necessarily represent all disability support recipients, they do represent a sizable number of individuals in receipt of government funded services. A future research priority therefore would include expanding the study group to include participants in receipt of other disability support services. The different disability profiles associated with the different support services would extend our understanding of the nature of support needs and factors that impact on support needs and cost of support provision. Apart from the work reported in Chapter 2 undertaken by Stancliffe and Keane (2000) and Stancliffe (2005), there is little published research from Australia on the factors associated with costs of service

provision or the relationship between costs and needs, indicating that this is another area for future research.

Caregivers in this research were asked to complete multiple scales on individuals in the study groups. The time and commitment required from caregivers to undertake these assessments meant it was impractical to recruit larger numbers of participants. Consequently, the sample size for this research have been small, restricting the exploratory capacity of the research. Of particular note was the impact of the limited numbers on the research reported in Chapter 8. As a result of the small sample size, it was not possible to consider the profiles for all coexisting disabilities present (e.g., hearing impairment and autism); and, as with the disabilities included in the study, these disabilities were also likely to impact on adaptive skill levels and consequent need for support. Further, within each of the disability subgroups considered in this study, individuals could potentially have other coexisting disabilities that may have confounded the study findings. By expanding the study sample size, it may be possible to investigate the impact of the additional disabilities and the interaction between coexisting disabilities, without the results being confounded by the presence of other coexisting disabilities.

The method used for rating disability severity in Chapter 7 was relatively unsophisticated. Severity of each disability was established using caregiver estimates instead of an objective measure of disability severity, due to a lack of standardised and universal measures that could be used across the range of disabilities considered. A future research priority would include developing an approach for determining the severity of different types of disabilities in a consistent manner. The use of the ICF scale is suggested, although the reliability of this would need to be investigated. Developing a reliable means of determining the severity of different types of disabilities would allow a more sophisticated model of cumulative severity to be established, enabling the impact of the cumulative effect of

coexisting disabilities to be examined. Improving our understanding of the impact of multiple disabilities, including the impact of the severity and nature of coexisting disabilities, has the potential to lead to better outcomes for individuals with intellectual disabilities. For example, understanding the nature and severity of disabilities present could facilitate the establishment of appropriately skilled interdisciplinary support teams. Further, the use of such interdisciplinary teams would ensure that funds allocated were more appropriately targeted towards services and supports (Kastner & Walsh, 2008).

Our understanding of the impact of disability severity and the interaction between particular coexisting disabilities could be further examined using an "outlier" analysis. Such an analysis might involve identifying individuals whose apparent need for support exceeds what might be expected on the basis of rated disability severity. Funding methodologies that use a deficits based model are likely to underestimate the need for support for these individuals. This is likely to mean they will be inadequately resourced monetarily to enable required supports to be purchased in individualised funding models. Alternately, in situations wherein funding resources are individually determined and then subsequently pooled to support a group of individuals (e.g., a group home situation), in order to address the person's support needs it is possible that services will need to draw on resources intended for others in the group. Such an outlier analysis could involve both reviews of a quantitative nature (e.g., conducting further assessments to establish disability severity and/or quantify level of support needed); and/or qualitative reviews (e.g., case studies), to establish the unique characteristics of these individuals (e.g., the presence of particular coexisting disabilities, personal risk or vulnerability issues, factors external to the person such as those outlined in the environmental domain of the ICF). Understanding the impact of unique characteristics or interaction effects associated with particular coexisting disabilities may help with the process of refining funding formulas. Further, findings from such analyses may help with establishing whether or not it is

possible to develop a model that is suitable for establishing funding levels for all disability types or for different types of support services; alternately, it may be that different funding models are required to address the differences in types of supports required due to the nature of the service (e.g., supports required for daily living tasks compared to behavioural supports) or nature of the disabilities (Severance, 2007).

A further problem associated with the small size of the study samples in this research, was the restricted range of intellectual disability impairment levels, with most study participants having moderate to severe levels of impairment. Expanding the sample size to increase representation within the mild and profound impairment categories would further help to clarify the impact of disability severity of adaptive behaviours and support needs (including medical/health and behavioural supports). Further, expanding the numbers of study participants would also enable factor studies to examine differences in factor structures associated with severity of intellectual impairment as well as across age groups.

As indicated in Chapter 3, old rules of thumb regarding the size of the sample required to enable recovery of factor loadings that are good estimates of the population loadings in factor analysis are no longer considered to be accurate. Instead, research by MacCallum et al. (1999) has demonstrated that sample size is dependent on variable and study characteristics, and particularly the level of communality is crucial in establishing sample sizes. For studies employing small samples, high communalities are considered necessary to reproduce population loadings, whereas lower communalities are required for larger sample sizes. Expanding the number of study participants would mean variables with lower communalities could be included in the analysis and as such would facilitate the analysis of a broader range of variables. Further factor analysis investigations could include item analyses of support needs scales to investigate the possibility of a hierarchical structure for support needs. Additionally, the use of other adaptive behaviour and support needs instruments would allow

an investigation of the extent to which the findings reported here are specific to the instruments investigated or whether it is possible to generalise the findings regarding the nature of the relationship between adaptive behaviours and support needs. A further factor analysis research possibility would involve expanding the types of variables included in the analysis, such as suggested and/or undertaken by Bruininks, Chen, Lakin, and McGrew (1992), Mathias and Nettelbeck (1992), and McGrew and Bruininks (1990) to establish the relationship of support needs to the major components of personal competence, as well as factors associated with community integration and adjustment. This type of research would involve factor analysis of support variables as well as variables considered to be measuring the dimensions of personal competence and the dimensions considered as typifying community adjustment. These dimensions include recreation/leisure integration, social networks integration, residential environment integration, employment/economic integration, need for social support services, and personal satisfaction (Bruininks et al., 1992). This type of research, although ambitious, would guide the development of future instruments by informing the nature of the dimensions for inclusion in a scale.

9.5 Conclusion

Need identification is an important priority for funding bodies distributing resources for the provision of disability support services. Central to the move from traditional funding approaches to individualised models is the issue of equity. The use of adaptive behaviour instruments for the purpose of need identification underscores the close relationship thought to exist with support needs. This thesis has examined this relationship, as well as examining disability factors that impacted on both adaptive behaviours and need for supports for individuals with intellectual disabilities. Investigations supported the notion that adaptive behaviours and support needs are closely related and similarly impacted by the number and severity of additional disabilities present; yet investigations also revealed slight differences

regarding underlying dimensional structure and in terms of the impact of the nature of coexisting disabilities. Nevertheless, the closeness of the two constructs does suggest cooperative use of the instruments for the purpose of resource allocation; for example, to refine or review decisions regarding level of funding or for checking the integrity of support data collected.

Adaptive behaviour and support scales appear to address very similar dimensions associated with tasks of daily living, including skills associated with personal self-sufficiency (i.e., practical dimension), community self-sufficiency (i.e., conceptual dimension) and personal-social responsibility (i.e., social dimension); although empirical findings in this research did not always support this correspondence. Further, both of the scale types address the area of challenging behaviour; yet the impact of challenging behaviour on need for supports remains unclear and requires further investigation. The support scales considered in this research addressed areas not covered by adaptive behaviour scales. In particular, they assessed need for support in the areas of medical/health issues, night support, and protection and advocacy, each of which was found to be important for individuals with intellectual disabilities and other coexisting disabilities, and all of which have important implications for funding supports. In addition to the areas currently addressed, the literature reviewed has suggested that the assessment of environmental factors will also be important in determining need for support. The literature reviewed and the findings of this research have also highlighted the importance of identifying training needs, rather than just addressing needs that focus on the maintenance of basic physiological functions and safety, with both long term monetary savings and enhanced quality of life as possible outcomes of such an assessment focus.

While providing assessment of a broader range of domains than the adaptive behaviour scales, the empirical findings and literature reviewed indicated that the assessment

approach utilised in the support scales presents noteworthy challenges. In particular, as suggested by Thompson et al. (2008) the assessment approach used in support scales such as SIS, as well as the nature of the items assessed, are more challenging than those contained within adaptive behaviour instruments. Consequently, familiarity and training, and the use of multiple informants, are likely to be important in order to obtain reliable and accurate ratings of level of need. Accuracy of the information collected will lead to improved equity of resource allocation, as well as improving the capacity of funding bodies to measure and monitor outcomes achieved for the money expended.

In concluding, there are two caveats that should be noted with regard to the development and use of support needs systems. In particular, the goal of introducing needs based assessment systems for the purpose of funding supports services is equity of resource distribution, such that individuals with greater levels of need should have more resource funds directed towards supporting them. Yet the literature reviewed in Chapter 2 has indicated that improved consumer outcomes and enhanced quality of life will not necessarily result simply from the presence of more support staff. Rather enhanced outcomes are likely to result from a combination of factors such as aspects of the service design (i.e., level of community integration, location and size of a facility, etc.) and features associated with service processes, such as the use of Active Support procedures. This procedure, as previously discussed, involves training for caregivers on the provision of effective support, as well as activity and support planning procedures, which focus on resident involvement in decision making and individualisation of preferences. The second caveat relates to the possible use of support needs measures to screen individuals out from receiving services, along the same lines that adaptive behaviours have been criticised as leading to the exclusion of individuals from participation in activities, due to the identification of deficits. That is, the risk exists that individuals will be excluded from receiving services, based on their assessed levels of need, if

the funding provided is not commensurate with the actual cost of providing the identified supports for individuals. Ultimately, consumer outcomes and particularly, the extent to which such a system leads to improvements in quality of life and opportunities for self-determination for consumers should be the measure of effectiveness for any needs based assessment and funding system.

References

American Association on Mental Retardation AAMR. (2003a). Shaping our destiny: A provider's guide to quality community services for people with developmental disabilities and their families. Washington, DC: Author.

American Association on Mental Retardation AAMR. (2003b). *Supports Intensity Scale*. Retrieved September 30, 2003, from http://www.aamr.org

Australian Institute of Health and Welfare AIHW. (2002a). *Data guide: Data items and definitions 2002 - 2003*. Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW. (2002b). *Disability Support Services 2002: National data on services provided under the Commonwealth/State Disability Agreement*. (AIHW cat. no. DIS 31). Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW. (2002c). *Unmet need for disability services: Effectiveness of funding and remaining shortfalls*. (AIHW cat. no. DIS 26). Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW. (2003). *Disability prevalence and trends*. (AIHW cat. no. DIS 34). Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW, (2004). *Disability and its relationship to health conditions and other factors*. (AIHW cat. no. DIS 37). Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW. (2005). *Disability Support Services 2003-04: National data on services provided under the Commonwealth/State Disability Agreement*. (AIHW cat. no. DIS 40). Canberra, ACT: Author.

Australian Institute of Health and Welfare AIHW (2007). Interactive Disability Data: 2004-05 CSTDA NMDS service user data [Data file]. Available from the AIHW website, http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20045

Aiken, L. R. (2000). *Psychological testing and assessment* (9th ed.). Boston, MA: Allyn & Bacon.

Aman, M. G., Richmond, G., Stewart, A. W., Bell, J. C., & Kissell, R. C. (1987). The Aberrant Behavior Checklist: Factor structure and the effect of subject variables in American and New Zealand facilities. *American Journal of Mental Deficiency, 91*, 570-578.

American Psychiatric Association APA (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV* (4th ed.). Washington, DC: Author.

Andrews, G., Peters, L., & Teeson, M. (1994). *Measurement of consumer outcome in mental health. A report to the national Mental Health Information Strategy Committee.* Canberra: Australian Government Publishing Service.

Annison, J., Jenkinson, J., Sparrow, W., & Bethune, E. (1996). *Disability*. South Melbourne, Victoria: Nelson Thomson Learning.

Arndt, S. (1981). A general measure of adaptive behavior. *American Journal of Mental Deficiency, 85*, 554-556.

Ashbaugh, J., & Nerney, T. (1990). Costs of providing residential and related support services to individuals with mental retardation. *Mental Retardation, 28*, 269-273.

Ashman, A. (1989). Change and disability services in Australia. A ten year retrospective. *Australia and New Zealand Journal of Developmental Disabilities, 15*, 73-80.

Bach, M. (2000, July). *Individualized funding and self determination: Making sure the means does not become the end.* Paper presented at the First International Conference on Self-Determination and Individualized Funding, Seattle, Washington, USA.

Baldwin, S. (1986). Problems with needs - where theory meets practice. *Disability Handicap and Society, 1*, 139-145.

Baume, P., & Kay, K. (1995). *Working solution: Report of the strategic review of the Commonwealth Disability Services Program*. Canberra, ACT: Australian Government Publishing Service.

Beange, H., Lennox, N., & Parmenter, T. R. (1999). Health targets for people with an intellectual disability. *Journal of Intellectual and Developmental Disability, 24*, 283-297.

Bleasdale, M. (2000, July). *Regulating IF - the case for union involvement.* Paper presented at the First International Conference on Self-Determination and Individualized Funding, Seattle, Washington, USA.

Bölte, S., & Poustka, F. (2002). The relation between general cognitive level and adaptive behavior domains in individuals with autism with and without co-morbid mental retardation. *Child Psychiatry and Human Development, 33*, 165-172.

Bowley, C., & Kerr, M. (2000). Epilepsy and intellectual disability. *Journal of Intellectual Disability Research, 44*, 529–543.

Bradshaw, J. (1977). The concept of social need. In N. Gilbert & H. Specht (Eds.), *Planning for social welfare: Issues, models and tasks*. (pp. 290-296). Engelwood Cliffs, New Jersey: Prentice Hall.

Bredkjaer, S., Mortensen, P. B., & Parnas, J. (1998). Epilepsy and non-organic non-affective psychosis: National epidemiologic study. *British Journal of Psychiatry, 172*, 235-238.

Brewin, C. R., Wing, J. K., Mangen, S. P., Brugha, T. S., & MacCarthy, B. (1987). Principles and practice of measuring needs in the long-term mentally ill: The MRC Needs for Care Assessment. *Psychological Medicine, 17*, 971-981.

Brown, E. C., Aman, M. G., & Havercamp, S. M. (2002). Factor analysis and norms for parent ratings on the Aberrant Behavior Checklist-Community for young people in special education. *Research in Developmental Disabilities, 23*, 45-60.

Bruininks, R., Hill, B., Weatherman, R., & Woodcock, R. (1986). *ICAP Inventory for Client and Agency Planning Examiners Manual.* Chicago: Riverside.

Bruininks, R., McGrew, K., & Maruyama, G. (1988). Structure of adaptive behavior in samples with and without mental retardation. *American Journal on Mental Retardation, 93*, 265-272.

Bruininks, R. H., Chen, T. H., Lakin, K. C., & McGrew, K. S. (1992). Components of personal competence and community integration for persons with mental retardation in small residential programs. *Research in Developmental Disabilities, 13*, 463-479.

Butterworth, J. (2002). From programs to supports. In R. L. Schalock, P. C. Baker & M. D. Croser (Eds.), *Embarking on a new century. Mental retardation at the end of the 20th century* (pp. 83-101). Washington, DC: American Association on Mental Retardation.

Campbell, E. M., Fortune, J., & Heinlein, K. B. (1998). The effects of funding packages on the outcomes of integration and independence of adults with developmental disabilities in two rural states. *Journal of Developmental and Physical Disabilities, 10*, 257-281.

Campbell, E. M., Fortune, J. R., Frisch, J. K., Heal, L. W., Heinlein, K. B., Lynch, R. M., & Severance, D. D. (2005). Predictors of expenditures in western states. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 175-201). Baltimore: Paul H. Brookes Publishing Co.

Campbell, E. M., & Heal, L. W. (1995). Prediction of cost, rates, and staffing by provider and client characteristics. *American Journal on Mental Retardation, 100*, 17-35.

Carroll, J. B. (1993). *Human cognitive abilities: A survey of factor-analytic studies*. Cambridge: Cambridge University Press.

Carvill, S. (2001). Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research, 45*, 467-483.

Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research, 1*, 245-276.

Caudrey, D. (2003, Winter) Brokerage. *South Australian Department of Human Services Disability Matters* p.1.

Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D., & Kromberg, J. G. R. (2002). Children with intellectual disability in rural South Africa: Prevalence and associated disability. *Journal of Intellectual Disability Research, 46*, 179-186.

Cicchetti, D. V., & Sparrow, S. A. (1981). Developing criteria for establishing interrater reliability of specific items: Applications to assessment of adaptive behavior. *American Journal of Mental Deficiency, 86*, 127-137.

Cocks, E., & Stehlick, D. (1996). History of services. In J. Annison, J. Jenkinson, W. Sparrow, & E. Bethune (Eds.), *Disability. A guide for health professionals* (pp. 8-33). Melbourne, Australia: Nelson Thomson Learning.

Cohen, P. (1982). To be or not to be: Control and balancing of Type I and Type II errors. *Evaluation and Program Planning, 5*, 247-253.

Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry, 190*, 27-35.

Cortese, L., Malla, A. K., McLean, T., & Diaz, J. F. (1999). Exploring the longitudinal course of psychotic illness: A case-study approach. *Canadian Journal of Psychiatry, 44*, 881-886.

Craig, E. M., & Tasse, M. J. (1999). Cultural and demographic group comparisons of adaptive behavior. In R. L. Schalock & D. L. Braddock (Eds.), *Adaptive behavior and its measurement: Implications for the field of mental retardation* (pp. 119-139). Washington, DC: American Association on Mental Retardation.

Crews, W. D., Bonaventura, S., & Rowe, F. (1994). Dual diagnosis: Prevalence of psychiatric disorders in a large state residential facility for individuals with mental retardation. *American Journal on Mental Retardation, 98*, 724-731.

Cunningham, T., & Presnall, D. (1978). Relationship between dimensions of adaptive behavior and sheltered workshop productivity. *American Journal of Mental Deficiency, 82*, 386-393.

Curtis, W. S., Donlon, E. T., & Tweedie, D. (1975). Adjustment of deaf-blind children. *Education of the Visually Handicapped, 7*, 21-26.

de Bildt, A., Kraijer, D., Sytema, S., & Minderaa, R. (2005). The psychometric properties of the Vineland Adaptive Behavior Scales in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 35*, 53-62.

Deb, S., & Hunter, D. (1991). Psychopathology of people with mental handicap and epilepsy. I: Maladaptive behaviour. *British Journal of Psychiatry, 159*, 822-826.

Deb, S., & Hunter, D. (1991). Psychopathology of people with mental handicap and epilepsy. II: Psychiatric illness. *British Journal of Psychiatry, 159*, 826-830.

Dekker, M. C., Nunn, R. J., Einfeld, S. E., Tonge, B. J., & Koot, H. M. (2002). Assessing emotional and behavioral problems in children with intellectual disability: Revisiting the factor structure of the Developmental Behavior Checklist. *Journal of Autism and Developmental Disorders, 32*, 601-610.

Department of Human Services DHS, (2003a). *Disability Services Framework 2004 - 2007 Draft*. Adelaide, SA: Department of Human Services, Social Justice and Country Division.

Department of Human Services DHS. (2003b). *Working with Aboriginal people a cultural guide: For community-based health and home care services in Wakefield, Gawler and Mid North Areas of rural South Australia*. Adelaide, SA: Department of Human Services, Social Justice and Country Division.

Di Nuovo, S. F., & Buono, S. (2007). Psychiatric syndromes comorbid with mental retardation: Differences in cognitive and adaptive skills. *Journal of Psychiatric Research, 41*, 795-800.

Doll, E. A. (1947). *Vineland Social Maturity Scale.* Oxford, England: Educational Test Bureau.

Doll, E. A. (1948). What is a moron? *The Journal of Abnormal and Social Psychology, 43*, 495-501.

Dowson, S., & Salisbury, B. (1999). *Individualized funding: Emerging policy issues*. Retrieved June 9, 2004, from http://www.individualizedfunding.com\documents_and_links.htm#IF

Dowson, S., & Salisbury, B. (2002). *Individualized Funding: Changing systems to support self-determination*. Retrieved June 9, 2004, from http://www.emprise-international.com.

Drews, C. D., Yeargin-Allsopp, M., Decouflé, P., & Murphy, C. C. (1995). Variation in the influence of selected sociodemographic risk factors for mental retardation. *American Journal of Public Health, 85*, 329-334.

Dykens, E. M., Hodapp, R. M., & Evans, D. W. (2006). Profiles and development of adaptive behavior in children with Down Syndrome. *Down Syndrome Research and Practice, 9*, 45-50.

Dyson, M., Vilé, S., & Allen, F. (2002). *Review of Accommodation Support Funding Process*. Perth WA: Disability Services Commission, Government of Western Australia.

Dyson, M., Allen, F., & Duckett, S. (2000). Profiling childhood disability: The reliability of the Educational Needs Questionnaire. *Evaluation and Program Planning, 23*, 177-185.

Dyson, M., Duckett, S. J., & Allen, F. C. L. (2000). A therapy-relevant casemix classification system for school aged children with disabilities. *Archives of Physical Medicine and Rehabilitation, 81*, 634-643.

Emerson, E. (1999). Residential supports for people with intellectual disabilities: Questions and challenges from the UK. *Journal of Intellectual and Developmental Disability, 24*, 309-319.

Emerson, E. & Hatton, C. (1996) Deinstitutionalisation in the UK and Ireland: Outcomes for service users. *Journal of Intellectual and Developmental Disability, 21*, 17-37.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Jarbrink, K., Knapp, M., Netten, A., & Walsh, P. N. (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation, 106*, 401-415.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Jarbrink, K., Netten, A., & Linehan, C. (2000). The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities. *Journal of Intellectual and Developmental Disability, 25*, 263-279.

Emerson, E., Robertson, J., Hatton, C., Knapp, M., Walsh, P. N., & Hallam, A. (2005). Costs and Outcomes of Community Residential Supports in England. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities*. Baltimore: Paul H. Brookes Publishing Co.

Espie, C. A., Pashley, A. S., Bonham, K. G., Sourindhrin, I., & O'Donovan, M. (1989). The mentally handicapped person with epilepsy: A comparative study investigating psychosocial functioning. *Journal of Mental Deficiency Research, 33*, 123-135.

Evans, J. (2000, July). *Guidelines for allocating individual funding - making sure it is fair.* Paper presented at the First International Conference on Self-Determination and Individualized Funding, Seattle, Washington, USA.

Evans, L. D., & Bradley-Johnson, S. (1988). A review of recently developed measures of adaptive behavior. *Psychology in the Schools, 25*, 276-287.

Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research, 45*, 457-464.

Felce, D. (1994). Costs, quality and staffing in services for people with severe learning disabilities. *Journal of Mental Health, 3*, 495-506.

Felce, D. (1998). The determinants of staff and resident activity in residential services for people with severe intellectual disability: Moving beyond size, building design, location and number of staff. *Journal of Intellectual and Developmental Disability, 23*, 103-119.

Felce, D., & Emerson, E. (2005). Community living: Costs, outcomes, and economies of scale: Findings from U.K. research. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 45-62). Baltimore: Paul H. Brookes Publishing Co.

Felce, D., Jones, E., Lowe, K., & Perry, J. (2003). Rational resourcing and productivity: Relationships among staff input, resident characteristics, and group home quality. *American Journal on Mental Retardation, 108*, 161-172.

Felce, D., Lowe, K., Beecham, J., & Hallam, A. (2000). Exploring the relationship between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviours in Wales: A multivariate regression analysis. *Journal of Intellectual and Developmental Disability, 25*, 307-326.

Felce, D., Lowe, K., & Jones, E. (2002a). Association between the provision characteristics and operation of supported housing services and resident outcomes. *Journal of Applied Research in Intellectual Disabilities, 15*, 404-418.

Felce, D., Lowe, K., & Jones, E. (2002b). Staff activity in supported housing services. *Journal of Applied Research in Intellectual Disabilities, 15*, 388-403.

Felce, D., Lowe, K., Perry, J., Baxter, H., Jones, E., Hallam, A., & Beecham, J. (1998). Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: Processes, outcomes and costs. *Journal of Intellectual Disability Research, 42*, 390-408.

Felce, D., & Perry, J. (1995). The extent of support for ordinary living provided in staffed housing: The relationship between staffing levels, resident characteristics, staff:resident interactions and resident activity patterns. *Social Science and Medicine, 40*, 799-810.

Felce, D., & Perry, J. (2004). Resource input, service process and resident activity indicators in a Welsh national random sample of staffed housing services for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 127-132.

Felce, D., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E., & Knapp, M. (2008). Outcomes and costs of community living: Semi-independent living and fully staffed group homes. *American Journal on Mental Retardation, 113*, 87-101.

Field, A. (2003). *Discovering statistics using SPSS for Windows*. London: Sage Publications Ltd.

Forbes, F. (2000, July). *Put the cork back in the Moet: Early reflections on individualised funding in Queensland.* Paper presented at the First International Conference on Self-Determination and Individualized Funding, Seattle, Washington, USA.

Forsyth, B., & Winterbottom, P. (2002). Beds, budgets and burdens: Learning disability expenditure *v.* workload across English health authorities. *British Journal of Psychiatry, 181*, 200-207.

Fortune, J. R., Smith, G. A., Campbell, E. M., Clabby, R. T. II , Heinlein, K. B., Lynch, R. M., & Allen, J. (2005). Individual budgets according to individual needs: The Wyoming DOORS system. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 241-262). Baltimore: Paul H. Brookes Publishing Co.

Foster, R., & Nihira, K. (1969). Adaptive behavior as a measure of psychiatric impairment. *American Journal of Mental Deficiency, 74*, 401-404.

Fraiberg, S. (1977). *Insights from the blind*. New York: Basic Books.

Gallagher, J., & Teesson, M. (2000). Measuring disability, need and outcome in Australian community mental health services. *Australian and New Zealand Journal of Psychiatry., 34*, 850-855.

Gardner, H. (1993). *Multiple intelligences: The theory in practice*. New York: Basic Books.

Gatherer, A. J., & Sturmey, P. (1991). The psychometric properties of the Behaviour Assessment Record (the BAR schedule). *Journal of Mental Deficiency Research, 35*, 529-536.

Godfrey, H. P., Frost, S., Snelling, E., Knight, R. G., Shelton, E. J., & Longmore, B. E. (1986). AAMD Adaptive Behaviour Scale: Normative, reliability and validity data. *New Zealand Journal of Psychology, 15*, 62-67.

Gould, A. (1998). The Service Need Assessment Profile (Version 1.0) [Computer software and manual]. Sydney, Australia: ATG & Associates Pty Ltd.

Greenspan, S. (1999a). A contextualist perspective on adaptive behavior. In R. L. Schalock & D. L. Braddock (Eds.), *Adaptive behavior and its measurement: Implications for the field*

of mental retardation (pp. 61-80). Washington, DC: American Association on Mental Retardation.

Greenspan, S. (1999b). What is meant by mental retardation? *International Review of Psychiatry, 11*, 6-18.

Greenspan, S. (2003, August). *Inadequacy of current measures of adaptive behavior in Atkins cases.* Paper presented at the annual meeting of the American Psychological Association, Toronto, Canada.

Greenspan, S., & Driscoll, J. (1997). The role of intelligence in a broad model of Personal Competence. In D. P. Flanagan, J. L. Genshaft, & P. L. Harrison (Eds.), *Contemporary intellectual assessment theories, tests and issues* (pp. 131-150). New York: The Guilford Press.

Greenspan, S., & Granfield, J. M. (1992). Reconsidering the construct of mental retardation: Implications of a model of social competence. *American Journal on Mental Retardation, 96*, 442-453.

Greenspan, S., & McGrew, K. S. (1996). Response to Mathias and Nettelbeck on the structure of competence: Need for theory-based methods to test theory-based questions. *Research in Developmental Disabilities, 17*, 145-152.

Greenspan, S., Switzky, H. N., & Granfield, J. M. (1996). Everyday intelligence and adaptive behavior: A theoretical framework. In J. W. Jacobsen & J. A. Mulick (Eds.), *Manual of diagnosis and professional practice in mental retardation* (pp. 127-135). Washington DC: American Psychological Association.

Grossman, H. J. (1983). *Classification in mental retardation*. Washington, DC: American Association on Mental Deficiency.

Guarnaccia, V. J. (1976). Factor structure and correlates of adaptive behavior in noninstitutionalized retarded adults. *American Journal of Mental Deficiency, 80*, 543-547.

Guscia, R., Ekberg, S., Harries, J., & Kirby, N. (2006). Measurement of environmental constructs in disability assessment instruments. *Journal of Policy and Practice in Intellectual Disabilities, 3*, 173–180.

Guscia, R., Harries, J., Kirby, N., & Nettelbeck, T. (2006). Rater bias and the measurement of support needs. *Journal of Intellectual and Developmental Disability, 31*, 156-160.

Guscia, R., Harries, J., Kirby, N., Nettelbeck, T., & Taplin, J. (2005). Reliability of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability, 30*, 24-30.

Guscia, R., Harries, J., Kirby, N., Nettelbeck, T., & Taplin, J. (2006). Construct and criterion validities of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability, 31*, 148-155.

Gustavson, K. H., Umb-Carlsson, Õ., & Sonnander, K. (2005). A follow-up study of mortality, health conditions and associated disabilities of people with intellectual disabilities in a Swedish county. *Journal of Intellectual Disability Research, 49*, 905-914.

Hagerty, M. R. (1999). Testing Maslow's Hierarchy of Needs: National quality-of-life across time. *Social Indicators Research, 46*, 249-271.

Hallam, A., Knapp, M., Jarbrink, K., Netten, A., Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., & Durkan, J. (2002). Costs of village community, residential campus and dispersed housing provision for people with intellectual disability. *Journal of Intellectual Disability Research, 46*, 394-404.

Harries, J., Guscia, R., Kirby, N., Nettelbeck, T., & Taplin, J. (2005). Support needs and adaptive behaviors. *American Journal on Mental Retardation, 110*, 393-404.

Harries, J., Guscia, R., Nettelbeck, T., & Kirby, N. (in press). Impact of the number and severity of additional disabilities on adaptive behavior and support profiles for people with intellectual disabilities. *American Journal on Mental Retardation.*

Harrison, P. L. (1987). Research with adaptive behavior scales. *Journal of Special Education, 21*, 37-68.

Harrison, P. L. (1989). Adaptive behavior: Research to practice. *Journal of School Psychology, 27*, 301-317.

Hatton, C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Perry, J., Felce, D., Lowe, K., Walsh, P. N., Linehan, C., & Hillery, J. (2001). The Adaptive Behavior Scale-Residential and Community (part I): Towards the development of a short form. *Research in Developmental Disabilities, 22*, 273-288.

Hatton, C., Emerson, E., Robertson, J., Henderson, D., & Cooper, J. (1995). The quality and costs of residential services for adults with multiple disabilities: A comparative evaluation. *Research in Developmental Disabilities, 16*, 439-460.

Hatton, C., Emerson, E., Robertson, J., Henderson, D., & Cooper, J. (1996). Factors associated with staff support and user lifestyle in services for people with multiple disabilities: A path analytic approach. *Journal of Intellectual Disability Research, 40*, 466-477.

Hatton, D. D., Bailey, D. B. J., Burchinal, M. R., & Ferrell, K. A. (1997). Development growth curves of preschool children with vision impairments. *Child Development, 68*, 788-806.

Head, M. J., & Conroy, J. W. (2005). Outcomes of self-determination in Michigan: Quality and costs. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 219-240). Baltimore: Paul H. Brookes Publishing Co.

Heal, L. W., & Fujiura, G. T. (1984). Methodological considerations in research on residential alternatives for developmentally disabled persons. *International Review of Research in Mental Retardation, 12*, 206-237.

Heber, R. (1959). A manual on terminology and classification in mental retardation. *American Journal of Mental Deficiency, 64*, monograph supplement.

Heller, T. (2002). Residential settings and outcomes for individuals with intellectual disabilities. *Current Opinion in Psychiatry, 15*, 503-508.

Heller, T., Miller, A. B., & Hsieh, K. (2002). Eight-year follow-up of the impact of environmental characteristics on the well-being of adults with developmental disabilities. *Mental Retardation, 40*, 366-378.

Holden, B., & Gitlesen, J. P. (2004). The association between severity of intellectual disability and psychiatric symptomatology. *Journal of Intellectual Disability Research, 48*, 556-562.

Horn, J. L., & Cattell, R. B. (1966). Refinement and test of the theory of fluid and crystallized intelligence. *Journal of Educational Psychology, 57*, 253-270.

Huczynski, A. A., & Buchanan, D. A. (2007). *Organizational Behaviour: An Introductory text* (6th ed.). Harlow, England: Prentice Hall.

Hug, N., Barclay, A., Collins, H., & Lamp, R. (1978). Validity and factor structure of the Preschool Attainment Record in Head Start children. *Journal of Psychology, 99*, 71-74.

Huxley, N., & Baldessarini, R. (2007). Disability and its treatment in bipolar disorder patients. *Bipolar Disorders, 9*, 183-196.

Issakidis, C., & Teesson, M. (1999). Measurement of need for care: A trial of the Camberwell Assessment of Need and the Health of the Nation Outcome Scales. *Australian and New Zealand Journal of Psychiatry, 33*, 754-759.

Iverson, J. C., & Fox, R. A. (1989). Prevalence of psychopathology among mentally retarded adults. *Research in Developmental Disabilities, 10*, 77-83.

Jacobson, J. W., & Janicki, M. P. (1983). Observed prevalence of multiple developmental disabilities. *Mental Retardation, 21*, 87-94.

Jacobson, J. W., & Mulick, J. A. (Eds.). (1996). *Manual of diagnosis and professional practice in mental retardation*. Washington, DC: American Psychological Association.

Jenkinson, J. C., Sparrow, W. A., & Shinkfield, A. J. (1996). Cognitive and Motor Functions. In J. Annison, J. Jenkinson, W. Sparrow, & E. Bethune (Eds.), *Disability* (pp. 114-137). Melbourne, Australia: Nelson Thomson Learning.

Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D., & Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: The impact of training staff in active support. *Journal of Intellectual Disability Research, 43*, 164 -178.

Kaiser, H. F. (1960). The application of electronic computers to factor analysis. *Educational and Psychological Measurement, 20*, 141-151.

Kamphaus, R. W. (1987). Conceptual and psychometric issues in the assessment of adaptive behavior. *Journal of Special Education, 21*, 27-35.

Kapell, D., Nightingale, B., Rodriguez, A., Lee, J. H., Zigman, W. B., & Schupf, N. (1998). Prevalence of chronic medical conditions in adults with mental retardation: Comparison with the general population. *Mental Retardation, 36*, 269-279.

Kastner, T. A., & Walsh, K. K. (2008). Divided we stand, united we fall: Personal budgets versus universal coverage. *Intellectual and Developmental Disabilities, 46*, 239-242.

Katz-Garris, L., Hadley, T. J., Garris, R. P., & Barnhill, B. (1980). A factor analytic study of the Adaptive Behavior Scale. *Psychological Reports, 47*, 807-814.

Kerr, A. M., McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, T., Beaton, P., Wallace, S., Newell, E., Eccles, T., & Prescott, R. J. (2003). Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports. *Journal of Intellectual Disability Research, 47*, 134-145.

Kerr, M. (2001). Clinical guidelines for the management of epilepsy in adults with an intellectual disability. *Seizure, 10*, 401-409.

Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalization for people with intellectual disability: A review of US studies conducted between 1980 and 1999. *Journal of Intellectual and Developmental Disability, 26*, 35-50.

Kirby, N. (2006, September). *The challenge of valid assessment: The need for instruments with an auditing capacity*. Paper presented at the 41st Annual Australasian Society for the Study of Intellectual Disability (ASSID) Conference, Canberra, Australia.

Kirby, N., Nettelbeck, T., Taplin, J., Guscia, R., Harries, J., Partridge, K., Thomson, S., & Wyatt, K. (2004 March). *Evaluating the Service Need Assessment Profile (SNAP).* Paper presented at the National Accommodation and Community Support Conference, Melbourne, Victoria.

Klin, A., Saulnier, C. A., Sparrow, S. S., Cicchetti, D. V., Volkmar, F. R., & Lord, C. (2007). Social and communication abilities and disabilities in higher functioning individuals with autism spectrum disorders: The Vineland and the ADOS. *Journal of Autism and Developmental Disorders, 37*, 748-759.

Klove, H., & Matthews, C. G. (2003). Psychometric and adaptive abilities in epilepsy with differential etiology. *Epilepsy and Behavior, 4*, 366-370.

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2002). Psychiatric disorders in children with intellectual disability. *Nordic Journal of Psychiatry, 56*, 126-131.

Kraijer, D. (2000). Review of Adaptive behavior studies in mentally retarded persons with autism/pervasive developmental disorder. *Journal of Autism and Developmental Disorders, 30*, 39-47.

La Malfa, G., Notarelli, A., Hardoy, M. C., Bertelli, M., & Cabras, P. L. (1997). Psychopathology and mental retardation: An Italian epidemiological study using the PIMRA. *Research in Developmental Disabilities, 18*, 179-184.

Lakin, K. C., Hewitt, A., Larson, S. A., & Stancliffe, R. J. (2005). Home and Community-Based Services: Costs, utilization, and outcomes. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 91-128). Baltimore: Paul H. Brooks Publishing Co.

Lakin, K. C., & Stancliffe, R. J. (2005). Expenditures and outcomes: Directions in financing, policy, and research. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 313-337). Baltimore: Paul H. Brookes Publishing Co.

Lambert, N. M., & Nicoll, R. C. (1976). Dimensions of adaptive behavior of retarded and nonretarded public-school children. *American Journal of Mental Deficiency, 8*, 135-146.

Laragy, C. (2002). *Individualised funding in disability services.* In T. Eardley and B. Bradbury (Eds.), *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001* (pp. 263-278). SPRC Report 1/02, Social Policy Research Centre, University of New South Wales.

Larson, S. A., Lakin, K. C., & Hewitt, A. S. (2002). Direct support professionals: 1975-2000. In R. L. Schalock, P. C. Baker, & M. D. Croser (Eds.), *Embarking on a new century:*

Mental retardation at the end of the 20th century. Washington, DC: American Association on Mental Retardation.

Lawton, M. P., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. P. Lawton (Eds.), *The psychology of adult development and aging* (pp. 619-674). Washington, DC: American Psychological Association.

Leonard, H., & Wen, X. (2002). The epidemiology of mental retardation: Challenges and opportunities in the new millennium. *Mental Retardation and Developmental Disabilities Research Reviews, 8*, 117-134.

Levine, S., & Elzey, F. F. (1968). Factor analysis of the San Francisco Vocational Competency Scale. *American Journal of Mental Deficiency, 73*, 509-513.

Lewis, J., Tonge, B., Mowat, D., Einfeld, S., Siddons, H., & Rees, V. (2000). Epilepsy and associated psychopathology in young people with intellectual disability. *Journal of Paediatrics and Child Health, 36*, 172-175.

Lindsay, M. (1996). *Can good intentions ensure good outcomes? Commonwealth Disability Policy 1983-1995*. Canberra ACT Australia: Australian Parliamentary Library.

Lord, J., & Hutchinson, P. (2003). Individualised support and funding: Building blocks for capacity building and inclusion. *Disability and Society, 18*, 71-86.

Loveland, K. A., & Tunali-Kotoski, B. (1998). Development of adaptive behaviour in persons with mental retardation. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 521-541). Cambridge, UK: Cambridge University Press.

Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Reeve, A., Schalock, R. L., Snell, M. A., Spitalnik, D. M., Spreat, S., & Tasse, M. J. (2002). *Mental retardation: Definition, classification, and system of supports*. Washington, DC: American Association on Mental Retardation.

MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological Methods, 4*, 84-99.

MacMillan, D. L., Gresham, F. M., & Siperstein, G. N. (1993). Conceptual and psychometric concerns about the 1992 AAMR definition of mental retardation. *American Journal on Mental Retardation, 98*, 325-335.

Maher, R. (2003). *Evaluation of the Individual Support Package Program: A report on the evaluation of the Individual Support Package (ISP) program in the Australian Capital Territory*. Retrieved August 16, 2005, from http:www.dhcs.act.gov.au/DisabilityACT/Publications/evaluationfinal03.pdf.

Mangen, S., & Brewin, C. R. (1991). The measurement of need. In P. E. Bebbington (Ed.), *Social psychiatry: Theory, methodology, and practice.* (pp. 163-181): New Brunswick, NJ: Transaction Publishers.

Mansell, J., Beadle-Brown, J., MacDonald, S., & Ashman, B. (2003). Resident involvement in activity in small community homes for people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities, 16*, 63-74.

Marshall, M., Lockwood, A., Green, G., Zajac-Roles, G., Roberts, C., & Harrison, G. (2004). Systematic assessments of need and care planning in severe mental illness. Cluster randomised controlled trial. *British Journal of Psychiatry, 185*, 163-168.

Marshburn, E. C., & Aman, M. G. (1992). Factor validity and norms for the Aberrant Behavior Checklist in a community sample of children with mental retardation. *Journal of Autism and Developmental Disorders, 22*, 357-373.

Maslow, A. (1970). *Motivation and personality*. New York: Harper and Row.

Mathias, J. L., & Nettelbeck, T. (1992). Validity of Greenspan's models of adaptive and social intelligence. *Research in Developmental Disabilities, 13*, 113-129.

Mathias, J. L., Nettelbeck, T., & Willson, R. J. (1996). A reply to Greenspan and McGrew's "Need for theory-based methods to test theory-based questions". *Research in Developmental Disabilities, 17*, 153-160.

Matson, J. I., Bamburg, J. W., Mayville, E. A., & Khan, I. (1999). Seizure disorders in people with intellectual disability: An analysis of differences in social functioning, adaptive functioning and maladaptive behaviors. *Journal of Intellectual Disability Research, 43*, 531-539.

Matson, J. L., Mayville, E. A., Lott, J. D., Bielecki, J., & Logan, R. (2003). A comparison of social and adaptive functioning in persons with psychosis, autism, and severe or profound mental retardation. *Journal of Developmental and Physical Disabilities, 15*, 57-65.

McDermott, S., Moran, R., Platt, T., Wood, H., Isaac, T., & Dasari, S. (2005). Prevalence of epilepsy in adults with mental retardation and related disabilities in primary care. *American Journal on Mental Retardation, 110*, 48-56.

McGill, P., Hughes, D., Teer, K., & Rye, L. (2001). Variability in staff reports of the frequency of challenging behavior. *Research in Developmental Disabilities, 22*, 221-231.

McGrew, K., & Bruininks, R. (1990). Defining adaptive and maladaptive behavior within a model of personal competence. *School Psychology Review, 19*, 53-73.

McGrew, K., & Bruininks, R. H. (1989). The factor structure of adaptive behavior. *School Psychology Review, 18*, 64-81.

McGrew, K. S., Bruininks, R. H., & Johnson, D. R. (1996). Confirmatory factor analytic investigation of Greenspan's model of personal competence. *American Journal on Mental Retardation, 100*, 533-545.

McGrew, K. S., Ittenbach, R. F., Bruininks, R. H., & Hill, B. K. (1991). Factor structure of maladaptive behavior across the lifespan of persons with mental retardation. *Research in Developmental Disabilities, 12*, 181-199.

McGrother, C. W., Bhaumik, S., Thorp, C. F., Hauck, A., Branford, D., & Watson, J. M. (2006). Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications. *Seizure, 15*, 376-386.

McLaren, J., & Bryson, S. E. (1987). Review of recent epidemiological studies of mental retardation: Prevalence, associated disorders, and etiology. *American Journal of Mental Retardation, 92*, 243-254.

Meacham, F. R., Kline, M. M., Stovall, J. A., & Sands, D. I. (1987). Adaptive behavior and low incidence handicaps: Hearing and visual impairments. *Journal of Special Education, 21*, 183-196.

Meadow, K. (1980). *Deafness and child development*. Berkley, Los Angeles: University of California Press.

Meyers, C. E., Nihira, K., & Zetlin, A. (1979). The measurement of adaptive behavior. In N. R. Ellis (Ed.), *Handbook of mental deficiency: Psychological theory & research* (pp. 431-481). New Jersey: Hillsdale.

Millsap, P. A., Thackrey, M., & Cook, V. J. (1987). Dimensional structure of the Adaptive Behavior Inventory for Children (ABIC): Analyses and implications. *Journal of Psychoeducational Assessment, 5*, 61-66.

Moore K.D., VanHaitsma K., Curyto K., & Saperstein A. (2003) A pragmatic environmental psychology: A metatheoretical inquiry into the work of M. Powell Lawton. *Journal of Environmental Psychology*, 23, 471-482.

Morgan, C. L., Baxter, H., & Kerr, M. P. (2003). Prevalence of epilepsy and associated health service utilization and mortality among patients with intellectual disability. *American Journal on Mental Retardation, 108*, 293-300.

Moseley, C. E., Gettings, R. M., & Cooper, R. (2003). *Having it your way: Understanding state individual budgeting strategies.* Alexandria, VA: National Association of State Directors of Developmental Disability Services (NASDDDS).

Moseley, C. R., Gettings, R. M., & Cooper, R. E. (2005). Having it your way: A national study of individual budgeting practices within the states. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 263-288). Baltimore: Paul H. Brookes Publishing Co.

Moss, S. C., & Hogg, J. (1990). Factorial and hierarchical cluster analysis of the Adaptive Behavior Scales (Part 1&2) in a population of older people (50 Years +) with severe intellectual impairment (mental handicap). *Australia and New Zealand Journal of Developmental Disabilities, 16*, 381-392.

Murphy, C. C., Boyle, C., Schendel, D., Decoufle´, P., & Yeargin-Allsopp, M. (1998). Epidemiology of mental retardation in children. *Mental Retardation and Developmental Disabilities Research Reviews, 4*, 6-13.

Murphy, C. C., Yeargin-Allsopp, M., Decouflé, P., & Drews, C. D. (1995). The administrative prevalence of mental retardation in 10-year-old children in metropolitan Atlanta, 1985 through 1987. *American Journal of Public Health, 85*, 319-323.

Murphy, V. (1994). *Personalised funding: The key to flexible service provision.* Paper presented at the Triple-O-Forum, Griffith University, Brisbane, Australia.

Nihira, K. (1969a). Factorial dimensions of adaptive behavior in adult retardates. *American Journal of Mental Deficiency, 73*, 868-878.

Nihira, K. (1969b). Factorial dimensions of adaptive behavior in mentally retarded children and adolescents. *American Journal of Mental Deficiency, 74*, 130-141.

Nihira, K. (1976). Dimensions of adaptive behavior in institutionalized mentally retarded children and adults: Developmental perspective. *American Journal of Mental Deficiency, 81*, 215-226.

Nihira, K. (1978). Factorial descriptions of the AAMD Adaptive Behavior Scale. In W. A. Coulter & H. W. Morrow (Eds.), *Adaptive behavior: Concepts and measurements*. New York: Grune & Stratton.

Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1967). *AAMD Adaptive Behavior Checklist*. Washington, DC: American Association on Mental Deficiency.

Nihira, K., Leland, H., & Lambert, N. (1993). *AAMR Adaptive Behavior Scale - Residential and Community Examiner's Manual* (2nd ed.). Texas, US: Pro-ed.

Nihira, K., Price-Williams, D. R., & White, J. F. (1988). Social competence and maladaptive behavior of people with dual diagnosis. *Journal of the Multihandicapped Person, 1*, 185-199.

Nosek, M. A., & Fuhrer, M. J. (1992). Independence among people with disabilities: I. A heuristic model. *Rehabilitation Counseling Bulletin, 36*, 6-20.

Nunnally, J. (1967). *Psychometric theory*. New York: McGraw Hill.

O'Brien, J. (2001). *Paying customers are not enough. The dynamics of Individualized Funding*. Retrieved June, 9, 2004 from http://members.shaw.ca/bsalisbury/#Articles%20Critical%20of%20Individualized%20Funding

O'Brien, P., Thesing, A., Tuck, B., & Capie, A. (2001). Perceptions of change, advantage and quality of life for people with intellectual disability who left a long stay institution to live in the community. *Journal of Intellectual and Developmental Disability, 26*, 67-82.

Ohlin, J. (1999). *Unmet need in disability services: Shortfall or systematic failure?* Canberra, ACT: Parliament of Australia Parliamentary Library.

Owens, E. P., & Bowling, D. H. (1970). Internal consistency and factor structure of the Preschool Attainment Record. *American Journal of Mental Deficiency, 75*, 170-171.

Pearson, C. (2004). Keeping the cash under control: What's the problem with direct payments in Scotland? *Disability and Society, 19*, 3-14.

Perri, G. (2003). Giving consumers of British public services more choice: What can be learned from recent history? *Journal of Social Policy, 32*, 239-270.

Perry, J., & Felce, D. (2003). Quality of life outcomes for people with intellectual disabilities living in staffed community housing services: A stratified random sample of statutory, voluntary and private agency provision. *Journal of Applied Research in Intellectual Disabilities, 16*, 11-28.

Perry, J., & Felce, D. (2005). Factors associated with outcome in community group homes. *American Journal on Mental Retardation, 110*, 121-135.

Perry, J., Lowe, K., Felce, D., & Jones, S. (2000). Characteristics of staffed community housing services for people with learning disabilities: A stratified random sample of statutory, voluntary and private agency provision. *Health and Social Care in the Community, 8*, 307-315.

Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wilkes, T., Strathdee, G., Loftus, L., McCrone, P., & Hayward, P. (1995). The Camberwell Assessment of Need: The validity and reliability of an instrument to assess the needs of people with severe mental illness. *British Journal of Psychiatry, 167*, 589-595.

Porat, B. (1977). Guttman scale test for Maslow Need Hierarchy. *The Journal of Psychology, 97*, 85-92.

Preacher, K. J., & MacCallum, R. C. (2003). Repairing Tom Swift's electric factor analysis machine. *Understanding Statistics, 2*, 13-43.

Raghavan, R., Marshall, M., Lockwood, A., & Duggan, L. (2004). Assessing the needs of people with learning disabilities and mental illness: Development of the learning disability version of the Cardinal Needs Schedule. *Journal of Intellectual Disability Research, 48,* 25-36.

Reynolds, W. M. (1981). Measurement of personal competence of mentally retarded individuals. *American Journal of Mental Deficiency, 85,* 368-376.

Rhoades, J. A., & Altman, B. M. (2001). Personal characteristics and contextual factors associated with residential expenditures for individuals with mental retardation. *Mental Retardation, 39*, 114-129.

Riches, V. C. (2003). Classification of support needs in a residential setting. *Journal of Intellectual and Developmental Disability, 28,* 323-341.

Ridley, J., & Jones, L. (2003). Direct what? The untapped potential of direct payments to mental health service users. *Disability and Society, 18,* 643-658.

Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A., Carr, D., Lowe, K., Knapp, M., & Hallam, A. (2004). Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation, 109*, 332-344.

Rohde, J., Farmer, R., Glover, G., & Nursey, A. (1989). A method of displaying assessment information about people with multiple handicaps as a disability profile. *Journal of Mental Deficiency Research, 33*, 95-98.

Roszkowski, M. J., Spreat, S., & Waldman, R. (1983). A canonical correlation between adaptive and maladaptive aspects of adaptive behavior. *American Journal of Mental Deficiency, 88*, 225-228.

Royse, D., & Drude, K. (1982). Mental health needs assessment: Beware of false promises. *Community Mental Health Journal, 18*, 97-106.

Saetermoe, C. L., Scattone, D., & Kim, K. H. (2001). Ethnicity and the stigma of disabilities. *Psychology and Health, 16,* 699-714.

Salisbury, B. (1997). *Some frequently asked questions about individualized funding and service brokerage*. Retrieved June 7, 2004, from http://members.shaw.ca/bsalisbury/#individualized%20Funding

Salvia, J., & Ysseldyke, J. E. (1991). *Assessment* (5th ed.). Boston, MA: Houghton Mifflin Company.

Sandford, D. A., & Elzinga, R. H. (1987). Dimensions of adaptive behaviour of young adults with behaviour disorders. *Australia and New Zealand Journal of Developmental Disabilities, 13,* 195-199.

Sapnas, K., & Zeller, R. (2002). Minimizing sample size when using exploratory factor analysis for measurement. *Journal of Nursing Measurement, 10,* 135-154.

Schalock, R. L. (1999). The merging of adaptive behavior and intelligence: Implications for the field of mental retardation. In R. L. Schalock & D.L Braddock. (Eds.), *Adaptive behavior and its measurement: Implications for the field of mental retardation* (pp. 43-59). Washington, DC, USA: American Association on Mental Retardation.

Schalock, R. L. (2003). Mental retardation: A condition characterized by significant limitations in practical, conceptual, and social skills. In H. N. Switzky & S. Greenspan (Eds.), *What is mental retardation? Ideas for an evolving disability.* (pp. 271-283) Washington, DC: American Association on Mental Retardation.

Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies, 14,* 204-215.

Schalock, R. L., & Braddock, D. L. (Eds.). (1999). *Adaptive behavior and its measurement: Implications for the field of mental retardation.* Washington, DC: American Association on Mental Retardation.

Schalock, R. L., & Keith, K. D. (1986). Resource allocation approach for determining clients' need status. *Mental Retardation, 24,* 27-35.

Severance, D. D. (2007, May). *A comparison of the SIS and ICAP in predicting individual budget amounts.* Paper presented at the American Association on Intellectual and Developmental Disabilities Annual Meeting, Atlanta, GA.

Severance, D. D., & Campbell, E. M. (2008). *What is a funding formula?* In R. L. Schalock, J. R Thompson, & M. J. Tassé (Eds.), *AAIDD SIS White Paper Series* Retrieved July 8, 2008, from http//www.siswebsite.org/galleries/default-file/SISWP Resource Allocation.pdf

Silverman, W. P., Silver, E. J., Lubin, R. A., & Sersen, E. A. (1983). Structure of the Minnesota Developmental Programming System Behavioral Scales, Alternate Form C. *American Journal of Mental Deficiency, 88,* 170-176.

Silverstein, A. B., Ageno, D., Alleman, A. C., Derecho, K. T., Gray, S. B., & White, J. F. (1985). Adaptive behavior of institutionalized individuals with Down Syndrome. *American Journal of Mental Deficiency, 89,* 555-558.

Silverstein, B., Wothke, W., & Slabaugh, R. (1988). Toward parsimony with comprehensiveness: Management applications of MDPS factor scores. *Mental Retardation, 26*, 145-153.

Slade, M. (1994). Needs assessment. Involvement of staff and users will help to meet needs. *British Journal of Psychiatry, 165*, 293-296.

Slade, M., Loftus, L., Phelan, M., Thornicroft, G., & Wykes, T. (1999). *The Camberwell Assessment of Need.* London: Gaskell.

Slade, M., Phelan, M., & Thornicroft, G. (1998). A comparison of needs assessed by staff and by an epidemiologically representative sample of patients with psychosis. *Psychological Medicine, 28*, 543-550.

Slade, M., Phelan, M., Thronicroft, G., & Parkman, S. (1996). The Camberwell Assessment of Need (CAN): Comparison of assessments by staff and patients of the needs of the severely mentally ill. *Social Psychiatry and Psychiatric Epidemiology, 31*, 109-113.

Slone, M., Durrheim, K., Kaminer, D., & Lachman, P. (1999). Issues in the identification of comorbidity of mental retardation and psychopathology in a multicultural context. *Social Psychiatry and Psychiatric Epidemiology, 34*, 190-194.

Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: An update. *Advances in Psychiatric Treatment, 11*, 214-222.

Smith, P. (2003). Self-determination and independent support brokerage: Creating innovative second-level supports. *Mental Retardation, 41*, 290-298.

Song, A., Jones, S., Lippert, J., Metzgen, K., Miller, J., & Borreca, C. (1984). Wisconsin Behavior Rating Scale: Measure of adaptive behavior for the developmental levels of 0 to 3 years. *American Journal of Mental Deficiency, 88*, 401-410.

Spall, P., McDonald, C., & Zetlin, D. (2005). Fixing the system? The experience of service users of the quasi-market in disability services in Australia. *Health and Social Care in the Community, 13*, 56-63.

Spandler, H., & Vick, N. (2005). Enabling access to direct payments: An exploration of care co-ordinators decision-making practices. *Journal of Mental Health, 14*, 145-155.

Spandler, H., & Vick, N. (2006). Opportunities for independent living using direct payments in mental health. *Health and Social Care in the Community, 14*, 107-115.

Sparrow, S. S., Balla D, & Cicchetti, D. (1984). *Vineland Adaptive Behavior Scales, interview edition survey form manual.* Circle Pines, MN: American Guidance Service.

Sparrow, S. S., & Cicchetti, D. V. (1978). Behavior Rating Inventory for moderately, severely, and profoundly retarded persons. *American Journal of Mental Deficiency, 82*, 365-374.

Sparrow, S. S., & Cicchetti, D. V. (1984). The Behavior Inventory for Rating Development (BIRD): Assessments of reliability and factorial validity. *Applied Research in Mental Retardation, 5*, 219-231.

Spreat, S. (1982). The AAMD Adaptive Behavior Scale: A psychometric review. *Journal of School Psychology, 20*, 45-56.

Spreat, S. (1999). Psychometric standards for adaptive behavior assessment. In R. L. Schalock & D. L. Braddock (Eds.), *Adaptive behavior and its measurement: Implications for the field of mental retardation* (pp. 103-117). Washington, DC, USA: American Association on Mental Retardation.

Stainton, T., & Boyce, S. (2004). "I have got my life back": Users' experience of direct payments. *Disability and Society, 19*, 443-454.

Stancliffe, R. J. (1997). Community living-unit size, staff presence, and resident's choice making. *Mental Retardation, 35*, 1-9.

Stancliffe, R. J. (2004). [Review of the assessment scale *Supports Intensity Scale: Users manual*]. *Journal of Policy and Practice in Intellectual Disabilities, 1*, 182-183.

Stancliffe, R. J. (2005). Semi-independent living and group homes in Australia. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 129-150). Baltimore: Paul H. Brookes Publishing Co.

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability, 25*, 281-305.

Stancliffe, R. J., & Lakin, K. C. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal on Mental Retardation, 102*, 552-568.

Stancliffe, R. J., & Lakin, K. C. (2005a). Context and issues in research on expenditures and outcomes of community supports. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 1-22). Baltimore: Paul H. Brookes Publishing Co.

Stancliffe, R. J., & Lakin, K. C. (2005b). Individual budgets and freedom from staff control. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for*

people with intellectual disabilities. (pp. 203-218). Baltimore: Paul H. Brookes Publishing Co.

Stancliffe, R. J., Lakin, K. C., Shea, J. R., Prouty, R. W., & Coucouvanis, K. (2005). The economics of deinstitutionalization. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities.* (pp. 289-312). Baltimore: Paul H. Brookes Publishing Co.

Stark, S. (2001). Creating disability in the home: The role of environmental barriers in the United States. *Disability and Society, 16*, 37-49.

Sternberg, R. J. (1988). *The triarchic mind*. New York: Viking.

Stinnett, T. A., Fuqua, D. R., & Coombs, W. T. (1999). Construct validity of the AAMR Adaptive Behavior Scale-School:2. *School Psychology Review, 28*, 31-43.

Stromme, P., & Diseth, T. H. (2000). Prevalence of psychiatric diagnoses in children with mental retardation: Data from a population-based study. *Developmental Medicine and Child Neurology, 42*, 266-270.

Sturmey, P. (2001). An exploratory factor analysis of the ICAP maladaptive behavior items. *Journal of Developmental and Physical Disabilities, 13*, 137-140.

Sturmey, P., Matson, J. L., & Lott, J. D. (2004). The Factor Structure of the DASH-II. *Journal of Developmental and Physical Disabilities, 16*, 247-255.

Tasse, M., & Craig, E. M. (1999). Critical issues in the cross-cultural assessment of adaptive behavior. In R. L. Schalock & D. L. Braddock (Eds.), *Adaptive behavior and its measurement: Implications for the field of mental retardation* (pp. 161-183). Washington, DC: American Association on Mental Retardation.

Thackrey, M. (1991). A principal components analysis of the Comprehensive Test of Adaptive Behavior. *American Journal on Mental Retardation, 96*, 213-215.

Thompson, J. R. (2003, November). *The SIS: A new scale to measure support needs*. Paper presented at the National Association of State Directors of Developmental Disabilities Services (NASDDDS) 2003 Annual Meeting, Alexandria Virginia.

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. A., Schalock , R. L., Silverman, W., Tasse, M., & Wehmeyer, M. (2002). *Supports Intensity Scale: Standardization and Users Manual. Unpublished assessment scale.* Washington, DC: American Association on Mental Retardation.

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. A., Schalock, R. L., Silverman, W., Tasse, M. J. & Wehmeyer, M. (2004). *Supports Intensity Scale: Users manual*. Washington, DC: American Association on Mental Retardation.

Thompson, J. R, Hughes, C., Schalock, R. L., Silverman, W., Tasse, M. J., Bryant, B., Craig, E. M., & Campbell, E. M. (2002). Integrating supports in assessment and planning. *Mental Retardation, 40*, 390-405.

Thompson, J. R., McGrew, K. S., & Bruininks, R. H. (1999). Adaptive and maladaptive behavior: Functional and structural characteristics. In R. L. Schalock & D. L. Braddock (Eds.), *Adaptive behavior and its measurement: Implications for the field of mental retardation* (pp. 15-42). Washington, DC, USA: American Association on Mental Retardation.

Thompson, J. R., McGrew, K. S., & Bruininks, R. H. (2002). Pieces of the puzzle: Measuring the personal competence and support needs of persons with intellectual disabilities. *Peabody Journal of Education, 77*, 23-39.

Thompson, J. R., Tassé, M. J., & McLaughlin, C. A. (2008). Interrater reliability of the Supports Intensity Scale (SIS). *American Journal on Mental Retardation, 113*, 231-237.

Thurstone, L. L. (1938). *Primary mental abilities. Psychometric monographs (No.1).* Chicago: University of Chicago Press.

Torjman, S. (1996). *Dollars for services: A.k.a. individualised funding*. Retrieved June 10, 2004, from http://members.home.net/bsalisbury

Torjman, S. (2000). *Proposal for a national personal support fund*. Retrieved June 10, 2004, from http://members.shaw.ca/individualizedfunding/Materials.htm

Tossebro, J. (1995). Impact of size revisited: Relation of number of residents to self-determination and deprivatization. *American Journal on Mental Retardation, 100*, 59-67.

Traci, M. A., Seekins, T., Szalda-Petree, A., & Ravesloot, C. (2002). Assessing secondary conditions among adults with developmental disabilities: A preliminary study. *Mental Retardation, 40*, 119-131.

Turnbull, T. (1998). *A social history of disability services in South Australia and a review of previous, current and future policy directions*. Adelaide, SA: University of Adelaide.

van Isterdael, C. E. D., Stilma, J. S., Bezemer, P. D., & Tijmes, N. T. (2006). 6220 institutionalised people with intellectual disability referred for visual assessment between 1993 and 2003: Overview and trends. *British Journal of Ophthalmology, 90*, 1297-1303.

van Schrojenstein Lantman-de Valk, H. M. J. (2005). Health in people with intellectual disabilities: Current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities, 18*, 325-333.

Velicer, W. F., & Fava, J. L. (1998). Effects of variable and subject sampling on factor pattern recovery. *Psychological Methods, 3*, 231-251.

Vernon, P. E. (1950). *The structure of human abilities*. London: Methuen.

Vlaskamp, C. (2005). Interdisciplinary assessment of people with profound intellectual and multiple disabilities. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service providers' guide.* (pp. 39-51). Malden, MA: Blackwell Publishing.

Voelker, S., Shore, D., Hakim-Larson, J., & Bruner, D. (1997). Discrepancies in parent and teacher ratings of adaptive skills of 59 children with multiple disabilities. *Mental Retardation, 35*, 10-17.

Volkmar, F. R., Sparrow, S. S., Goudreau, D., Cicchetti, D. V., Paul, R., & Cohen, D. (1987). Social deficits in autism: An operational approach using the Vineland Adaptive Behavior Scales. *Journal of the American Academy of Child and Adolescent Psychiatry, 26*, 156-161.

Wahba, M. A., & Bridwell, L. G. (1976). Maslow reconsidered: A review of research on the need hierarchy theory. *Organizational Behavior and Human Performance, 15*, 212-240.

Walsh, K. K., Kastner, T. A., & Green, R. G. (2003). Cost comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation, 41*, 103-122.

Walsh, P. N., & McConkey, R. (1989). Dimensions of social competence in a population of adults with mental handicap. *Mental Handicap Research, 2*, 119-128.

Warburg, M. (2001). Visual impairment in adult people with intellectual disability: Literature review. *Journal of Intellectual Disability Research, 45*, 424-438.

Watkins, M. W., Ravert, C. M., & Crosby, E. G. (2002). Normative factor structure of the AAMR Adaptive Behavior Scale-School, Second Edition. *Journal of Psychoeducational Assessment, 20*, 337-345.

Whitaker, S., & Read, S. (2006). The prevalence of psychiatric disorders among people with intellectual disabilities: An analysis of the literature. *Journal of Applied Research in Intellectual Disabilities, 19*, 330-345.

White, P., Chant, D., Edwards, N., Townsend, C., & Waghorn, G. (2002). Prevalence of intellectual disability and comorbid mental illness in an Australian community sample. *Australian and New Zealand Journal of Psychiatry, 37*, 395-400.

Widaman, K. F. (1993). Common factor analysis versus principal component analysis: Differential bias in representing model parameters? *Multivariate Behavioral Research, 28*, 263-312.

Widaman, K. F., Borthwick-Duffy, S. A., & Little, T. D. (1991). The structure and development of adaptive behaviours. *International Review of Research in Mental Retardation, 17*, 1-54.

Widaman, K. F., Gibbs, K. W., & Geary, D. C. (1987). Structure of adaptive behavior: I. Replication across fourteen samples of nonprofoundly mentally retarded people. *American Journal of Mental Deficiency, 91*, 348-360.

Widaman, K. F., & McGrew, K. S. (1996). The structure of adaptive behavior. In J. W. Jacobson & J. A. Mulick (Eds.), *Manual of diagnosis and professional practice in mental retardation* (pp. 97-110). Washington DC: American Psychological Association.

Widaman, K. F., Stacy, A. W., & Borthwick-Duffy, S. A. (1993). Construct validity of dimensions of adaptive behavior: A multitrait-multimethod evaluation. *American Journal on Mental Retardation, 98*, 219-234.

Williams, V., Simons, K., Gramlich, S., McBride, G., Snelham, N., & Meyers, B. (2003). Paying the piper and calling the tune? The relationship between parents and direct payments for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 16*, 219-228.

World Health Organization WHO. (2001). *International Classification of Functioning, Disability and Health (ICF).* Geneva: Author.

Yang, K. S. (2003). Beyond Maslow's culture-bound linear theory: A preliminary statement of the double-y model of basic human needs. *Nebraska Symposium on Motivation, 49*, 175-255.

Yeatman, A. (1996). *Getting real: The interim report of the review of the Commonwealth/State Disability Agreement*. Canberra, ACT: Australian Government. Publishing Service.

Young, L., & Ashman, A. F. (2004). Deinstitutionalization for older adults with severe mental retardation: Results from Australia. *American Journal on Mental Retardation, 109*, 397-412.

Young, L., Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P. (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual and Developmental Disability, 23*, 155-170.

Zijlstra, H. P., & Vlaskamp, C. (2005). The impact of medical conditions on the support of children with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities, 18*, 151-161

APPENDIX A. Additional Publication Details

Guscia, R., Ekberg, S., Harries, J., & Kirby, N. (2006). Measurement of environmental constructs in disability assessment instruments. *Journal of Policy and Practice in Intellectual Disabilities, 3,* 173–180.

Guscia, R., Harries, J., Kirby, N., & Nettelbeck, T. (2006). Rater bias and the measurement of support needs. *Journal of Intellectual and Developmental Disability, 31,* 156-160.

Guscia, R., Harries, J., Kirby, N., Nettelbeck, T., & Taplin, J. (2005). Reliability of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability, 3,* 24-30.

Guscia, R., Harries, J., Kirby, N., Nettelbeck, T., & Taplin, J. (2006). Construct and criterion validities of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability, 3,* 148-155.

Appendix B. Published Version of Paper Presented as Chapter 6 (Support Needs and Adaptive Behaviours)

NOTE:
This paper is included as Chapter 6 and is also in the print copy of the thesis held in the University of Adelaide Library.