Income for adults with an intellectual disability

Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability

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Chapter one: Introduction

Adults with an intellectual disability do not usually earn very much money and some live in poverty. Poverty means not having enough money to pay for everyday needs like food, housing, transport and medical treatment. People who do not earn very much money also find it hard to take part in community life the way they might want to. This review of income looks at:

- why people with an intellectual disability do not earn very much money
- what this means to their lives
- why supported employment is positive for people
- benefits for people with and intellectual disability
- a new way of getting funding for disability support called individualised funding.

Chapter two: Income level and adults with an intellectual disability

Research shows that many people with an intellectual disability live in poverty. There are a number of reasons for why people are poor.

1. People with an intellectual disability often find it hard to get a job.
2. If people with an intellectual disability do work they often do not get paid very much, or they work part time.
3. Having a low paid job means that some people also need to get a benefit to be able to pay for their everyday needs.
4. Not being able to find a job at all means that some people need to be on a benefit for their whole life.

While it is true that many people with an intellectual disability are poor, researchers are now saying that just because someone has a disability they do not have to be poor. Instead, we need to find ways for people with an intellectual disability to get jobs, and we need to make sure that people get the benefits they should get. People with an intellectual disability themselves are now talking about work and saying how much money they earn. Most of all – people with an intellectual disability want to work but sometimes working does not mean they earn more money. Some people say they are not paid enough for the work they do. Other people with an intellectual disability are worried about what working does to their benefits. Sometimes their benefits give them more money than they would get from working.

Some researchers have said that people with an intellectual disability are poor for another reason. Some people with an intellectual disability need other people to help them manage their money. This could be the disability support service that they use, a family member, or another person like a lawyer. Sometimes a person's money is spent on things that they do not really want to spend it on, or in some cases, things that they do not know about. It is important that people with an intellectual disability learn more about their own money. They need to know how much they are paid or what benefits they get, as well as what their money is spent on.

Supported employment is when people with an intellectual disability are helped to find jobs, and supported by a special person called a "job coach" when they are working. Research has shown that people with an intellectual disability earn more money if they are in supported employment. Starting work for someone who has been on a benefit can also be hard. Some people do not want to take the risk of losing their benefits – especially if their job does not work out. For people who live in community homes, starting work can be very hard because they often have to use almost all of their benefits to pay for their accommodation.

Part of this review is about individualised funding. Individualised funding means that a person has money for disability services paid straight to them. At the moment the Government usually pays money for disability support to a disability support service and not to the person with a disability. When a person with an intellectual disability has the money paid to them to buy support for themselves they have to:

- decide what support they need
- decide what support services they want to use
- (in some cases) employ their own staff
- make sure they can say what they have spent the money on.

This is a way of getting money for support services that is very new to people with an intellectual disability. A lot of people with disabilities, and some disability service providers and researchers want to see individualised funding become possible for all people with disabilities. Some people say that individualised funding is a way for people with an intellectual disability to have more say in their lives. It can also be a good way to make sure that people get the kinds of services they want and need. Other people with disabilities have said that individualised funding is a lot of work that they do not always want to do. Most people with a intellectual disability have not heard of individualised funding and do not know much about it.

What needs to be done about income for New Zealand adults who have an intellectual disability?

- The Government needs to think about adults with an intellectual disability when they make changes to benefits, or develop new benefits.

- The Government needs to think about the amount that adults with an intellectual disability are paid. At the moment many people on benefits are very poor and do not have enough money to remain healthy, or to make life choices.

- Adults with an intellectual disability have to have more say in how their money is spent. They also need help to manage their own money if they want to.

- Adults with an intellectual disability must be able to work and to get work.

- The Government needs to make sure that people who work earn at least as much as they would on a benefit. That is – they do not lose money by working.

- Adults with intellectual disabilities need to know about what benefits they are allowed. They also need to know when the benefit system changes. They can then make **informed decisions** about their working life.

- Individualised funding is a new way of funding disability support. People with an intellectual disability themselves, disability service providers, families and the Government all need to think about individualised funding carefully if it is to be used in New Zealand.

CHAPTER ONE

INTRODUCTION

> *The social and economic status of people is largely determined by access to the labour market and their earning potential Exclusion from the labour market or marginalisation within it are the particular mechanisms by which certain groups are excluded from prosperity and influence. Disabled people are, in general, one group that is disadvantaged through limited access to the labour market. The social and economic consequences of this exclusion are great (Kitchin, Shirlow and Shuttleworth 1998: p 785)*

Adults with an intellectual disability typically experience low levels of income. In fact, many men or women with an intellectual disability live on or below the poverty line. This economic hardship manifests itself in the way in which people can meet their everyday needs including food, housing and medical treatment. Lack of income impacts negatively on the ability of men and women with an intellectual disability to participate in community life.

The low income levels of people with an intellectual disability can be attributed to the fact that employment opportunities for this group are very limited. Those who do work are often employed in low paid or part-time positions. The majority of people with an intellectual disability are, however, reliant on benefits to meet the costs of everyday living. Their ability to increase their income level is restricted by the interface between income support benefits and employment. For many, the risks of employment are too great. That is – employment opportunities are often turned down to avoid the loss of benefits. This review addresses these aforementioned issues and also explores individualised funding, a funding model that is increasingly being seen as an alternative to more traditional funding models for adults with an intellectual disability.

Conducting a review of income for adults with an intellectual disability presents some difficulties. The biggest challenge is summarising and making sense of information relating to income and adults with an intellectual disability that relates to a totally different country and, therefore, political and economic context. The benefit system is structured differently in Britain to that which is in place in North America, and obviously, to that available to New Zealand adults. What we have attempted to do is to include information relating to each context that highlights or illustrates issues that are (or may be) relevant to income and New Zealand adults with an intellectual disability.

Another methodological issue to mention is the use of the terms disability and intellectual disability. Much of the research literature in the area of income and income level considers disabled people in general Much of this information is relevant to understanding the experiences of people with an intellectual disability so it has been included for the purposes of the review. As a general rule where the term “people with disabilities” has been used, the literature has not specified disability groups. The term **intellectual disability** has been used when the literature being reviewed has specified the disability group being referred to.

This review is arranged in Chapters with each chapter focussing on an area pertinent to the area of Income for adults with an intellectual disability. Topics covered in each chapter are outlined below. In Chapter two the issue of income level for adults with an intellectual disability is discussed. Chapter three explores the links between supported employment and income. The interface between income and benefits is the focus of Chapter four, while Chapter five investigates individualised funding for adults with an intellectual disability. Chapter six summarises the major findings of this review of the literature and presents implications for policy, services, and research.

CHAPTER TWO

INCOME LEVEL AND ADULTS WITH AN INTELLECTUAL DISABILITY

Poverty and adults with an intellectual disability

Despite a growing emphasis on increasing opportunities for employment in the lives of adults with an intellectual disability, people with an intellectual disability continue to be one of the most disadvantaged groups in the labour market. Many people with an intellectual disability are excluded from work while others are frequently able only to work part-time. Research suggests that less than 10 percent of people with a severe intellectual disability are in paid employment and that the vast majority of people with an intellectual disability who do work are concentrated in low skilled, low waged jobs (Berry 1999). A significant number of people with an intellectual disability rely on a combination of benefits and earned income to meet their living and disability related costs. Alongside them are the many thousands of people with an intellectual disability who cannot enter the workforce and will depend **exclusively** on earning replacement benefits throughout their lives (Berry 1999).

Unfortunately, poverty is experienced all too frequently in the lives of people with an intellectual disability. A significant body of research is available that discusses the cause and impact of poverty in the lives of people with an intellectual disability. A recent paper by Butterworth and Gilmore (2000) articulates very clearly the issues that continue to have a negative impact on the ability of men and women with disabilities to earn an adequate income. Butterworth and Gilmore reported that individuals with disabilities participate in the labour force at consistently lower rates than individuals without disabilities. After analysing data from the national population survey, Butterworth and Gilmore suggest that in the American context there has actually been a decline in labour force participation of people with disabilities during the ten year period between 1987 and 1997.

Butterworth and Gilmore also highlight the issues of under-employment and high rates of poverty experienced by people with disabilities. The average income for people with disabilities in the United States is as much as one third lower than their non-disabled peers. For example, in 1997 the median annual earnings of men with disabilities was $10,562 compared to $30,466 for men without disabilities. Women with disabilities had median annual earnings of $8,124 compared to $20,311 for women without disabilities. Finally, Butterworth and Gilmore reported that based on family income 25 percent of men with disabilities and 32 percent of women with disabilities lived in a family with an income below the poverty line.

A framework for thinking about poverty

Beresford (1996) explores the relationship between poverty and disability, which he describes as being “close, complex and multifaceted”. The first point that he makes, challenges the commonly held assumption that if a person has an impairment then they will also be poor. In his view impairment is not only a function of poverty and nor is poverty restricted to disabled people. An analysis of disability based solely on poverty is, therefore, inaccurate and misleading. Disabled people are, however, over represented among poor people. This is true for all disabled groups (including people with an intellectual disability) with Beresford reporting that in Britain and the United States 60 percent of people with disabilities live **below** the poverty line.

Beresford contends that traditionally the debate about poverty has been a narrow and euro centric one, which has mainly been based on the perspectives, ideologies and interests of the non-poor and the non-disabled. In his view, the conventional poverty debate has been based on a social administration approach which has not integrated race, disability, age, sexual orientation, and gender into its analysis. Furthermore, outside of this conventional approach, very little research has focussed on the relationship between poverty and disability. Beresford states that "poor and disabled people continue to be marginalised in debates and developments around poverty".

The result of this common tendency to isolate and lump people together indiscriminately as poor obscures both people's differences and their shared oppressions. Beresford identifies two competing definitions of poverty as being central to the conventional poverty debate. The first he refers to as the **absolute** definition, which is related to the notion of the lack of basic necessities for life, and the second as the **relative deprivation** definition, based on not being able to live in accordance with the customs and values of the society of which a person is a part. While absolute poverty is more often associated with the developing world, both absolute and relative poverty are increasingly identified within Western countries.

Beresford points out that researchers have criticised both these definitions of poverty. The absolute definition of poverty fails to take adequate account of individual, occupational, cultural or ethnic differences; people's social and cultural needs, dietary, housing and other changes over time. Furthermore, it is presented as an objective scientific measure when it is actually based on externally imposed normative judgements. The relative definition of poverty is linked to existing patterns of consumption and with the increasing commodification of goods and services. In doing so it is focussed on the dominant customs, values and patterns of living, which may not be shared by everyone.

An alternative approach for understanding poverty has recently been put forward: the rights-based approach. This interpretation of poverty identifies the way in which civil, political, and social rights are weakened by poverty. It also focuses on the interrelationship of rights. For example, Beresford states that "the full and effective exercise of legal rights requires a firm base of social and economic rights". That is, poverty like other consequences of institutionalised discrimination facing disabled people, has the effect of restricting their rights. Consideration of the perspectives of people who experience poverty, and the perspectives of those involved in the disabled people's movement is critical to a greater understanding of the relationship between poverty and disability.

However, as mentioned earlier, poor people themselves have had minimal involvement in anti-poverty policy and campaigning. Poor people's exclusion from debates and developments that concern them, is very similar to the exclusion experienced by disabled people. Beresford reports that this marginalisation is slowly beginning to change. Some of the issues that have emerged as a result of the involvement of poor people, is a recognition that people do not like being labelled as poor or lumped together under this stigmatising label. It is also clear that poor people themselves conceive poverty as more than material deprivation of material rights. They also perceive poverty to be about the denial of rights, emotional insecurity, and the inability to maintain responsibilities as individuals, parents and citizens. Disabled people have also challenged the traditional conceptualisation of poverty (and also their exclusion from discussion and development of this issue). Disabled people's organisations have argued that poverty must be seen as one expression of the institutional discrimination that disabled people face.

Beresford also makes a link between poverty and the medical model of disability, arguing that poverty has traditionally been seen as a result of the inherent dependence of disabled people. Disabled people are structured as economically dependent through their reliance on state benefits or charitable giving. Beresford makes the following statement.

> *State income support systems generally perpetuate people's poverty, keeping them at or below socially-defined poverty lines, rather than lifting them out of poverty. They reflect the pre-occupation of the social administration approach to poverty with welfare solutions (p 557).*

Beresford also uncovers the link between poverty and what he refers to as disemployment. Central to the high level of poverty experienced by disabled people is their restricted access to employment. Inferior and segregated education, restricted access to training and further education, inaccessible and inflexible employment which reduces opportunities, and prejudice which labels people as incapable and unreliable have all been identified as factors which have contributed to low levels of employment for people with disabilities. Furthermore, paid work does not provide a "way out" of poverty because a disproportionate number of disabled people are confined to less secure, lower paid employment. In addition, the poverty experienced by people with disabilities is sometimes exacerbated by the additional costs associated with having an impairment. These needs continue regardless of whether a person with a disability is in paid employment or not.

Finally, Beresford also reflects on disabled people's diverse experiences of poverty. While poverty is widely experienced by people with disabilities, there are also significant differences in their experiences, which need to be recognised. For example, distinctions need to be drawn between the particular problems facing disabled children in poor families, the need for training and support for recently disabled people, and the needs of adults disabled from infancy. Women with disabilities are recognised as doubly disadvantaged with this group experiencing much lower rates of employment and receiving lower rates of pay if they are successful in securing employment.

Beresford suggests a number of strategies which he identifies as critical to alleviating and reducing poverty. Such strategies include:

- the full involvement of people with disabilities in the conceptualisation, analysis and discussion of poverty
- the economic inclusion of disabled people
- the reallocation of resources
- the full involvement of disabled people and their organisations in the development of anti-poverty policy

- supporting disabled people’s organisations and countering their impoverishment
- a changed role for state and government (whereby consideration of the needs of disabled people is an inherent part of all policies).

Income and women with an intellectual disability

That women earn less than men holds true for individuals with and without disabilities. With regard to women with disabilities in particular researchers have found that men with disabilities are more that twice as likely to be employed, and earn 44 percent more than women with disabilities (Traustadottir 1990).

Fulton and Sabornie (1994) comment on the evidence of employment inequality among women with disabilities by reviewing studies which have been concerned with employment outcomes of women and men with disabilities. An analysis of this information is then used to make recommendations for achieving better employment experiences for women with disabilities. Upon reviewing available research in the area of gender and employment, Fulton and Sabornie suggested that the equalisation of women with disabilities in employment should become a priority for transition related special education. Further to this point, they suggest that service providers need to find ways to increase the participation and success rate of women with disabilities in employment once they have left school. Further exploration of the differences and similarities of employment outcomes for women with and without disabilities is required, according to Fulton and Sabornie, as women with disabilities are as likely to be affected by gender as by disability.

In a review of Work for adults with an intellectual disability Bray (2003) articulated a need to address comprehensively the issue of work for women with an intellectual disability. Such attention is necessary if the income level of women with an intellectual disability is to increase.

Income in the New Zealand context

Research relating to the New Zealand context is consistent with the findings of overseas research on income levels and people with disabilities. In the document *Disability Counts* (1998), produced by Statistics New Zealand using the 1996 Household Disability Survey and the 1997 Disability Survey of Residential Facilities, important information emerged. For example, that people with disabilities are less likely to be employed was a significant finding of this survey. Correspondingly, the total personal income of those with a disability is significantly lower than that for adults without disabilities. Sixty percent of adults with a disability reported a gross personal income of less than $15,000. This compares with 45 percent for those without a disability. Fewer than 15 percent of adults with a disability received $30,000 or more.

Similarly to overseas research, women with disabilities had the lowest personal incomes with 71 percent reporting an annual personal income of less than $15,000. Only 8 percent of women with disabilities received in excess of $30,000 (as compared with over 22 percent of men with disabilities). Women were also found to be disadvantaged in terms of household income with adults with disabilities being almost twice as likely to have a household income under $30,000 than those without disabilities. Disability Counts also reported that people with disabilities are likely to have unmet needs for services or assistance and that the level of unmet need increases as the household income levels decline.

The views of adults with an intellectual disability

People with an intellectual disability are increasingly voicing their dissatisfaction with work and income. In particular, a distinct lack of earning power is seen as problematic. Tamara Kainova (2000), a woman with an intellectual disability reflected on the need for work and income.

> *We like working but we are not able to do anything. We would like to work like other people do. We also need to make some money to support ourselves. Nowadays our invalid pension is not enough and we cannot live properly without work. We are still young! (p 161).*

Sandra (2000), also a woman with an intellectual disability, clearly articulates the frustration she feels about her work and income situation.

> *I work half past nine to five-thirty Tuesdays, Wednesdays and Fridays. I get paid two pounds a day. Not a lot of money. Can't do anything with two pounds. Can't finish my driving lessons, can't help my daughter. I'm planning kids next year and it's not enough. I haven't said it to them yet, but I feel like saying it: TWO POUNDS IS NOT ENOUGH. Two pounds can't really help me. What can it buy? Sanitary towels, two bars of soap That's all. If you're like me, in my position, you need more money, to buy clothes and shoes. I'm not really paid. I'm doing labouring (p 28).*

The effects of inadequate income

> *As well as disabling policies and practice generating poverty among disabled people, notably through disabled people's marginalisation by and exclusion from the labour market, poverty generates ill health and impairment. This is true in both rich and poor societies. Poverty generates impairment by reducing intellectual abilities, causing immediate physical damage and leading to early onset frailty (Beresford 1996: p 564).*

Lynch, Kaplan and Shema (1997) reported that living with prolonged economic hardship affects people much like a chronic disease, by reducing physical and mental ability and impinging on routine activities of daily living.

The factors of race, poverty and ethnicity and how they affect the health care and support system provided to adults with an intellectual disability are explored in a paper by Robinson and Rathbone (1999). Robinson and Rathbone articulated the effects of poverty very clearly in the following statement:

> *Individuals with mental disabilities are more likely to live in poverty, including having poorer housing condition and higher exposure to high crime areas in which they are particularly vulnerable (p 334).*

Robinson and Rathbone also point out that individuals living in poverty are less likely to be insured, less likely to have access to a range of high quality services in the community, and receive less benefit from existing services than those who have greater financial resources. In short, those who are in most need of services experience decreased access to them.

One of the most troubling effects of poverty is explored by Drew (1998) who provides details of an Australian project that was developed in response to young people who were homeless and had an intellectual disability in the Brisbane area. The need for such a service was identified through earlier research, which involved the participation of 70 young people with a mild intellectual disability who were homeless, or were at risk of homelessness. The At Risk Resource and Outreach Service (ARROS) was established as a pilot project and commenced in 1996. Two people were employed in the roles of direct support workers and coordinator/resource workers. Young people within the ARROS group had experienced the following states of homelessness:

- being without shelter, “sleeping rough”
- living in unsafe environments
- moving regularly
- living with friends or relatives with limited resources
- living for short periods in boarding houses, hostels or caravan parks
- sleeping in tents
- sharing in a situation with little or no privacy
- not having access to shared accommodation when other residents are not at home (p 6).

Drew points out that young people with an intellectual disability are at risk of homelessness in similar ways to other people in the community. Drew argues, however, that the link between homelessness and experiences of social and economic disadvantage means that young people with an intellectual disability are more at risk. Poverty, unstable housing, social dislocation, and discriminatory social attitudes increase the risk for homelessness and are all common experiences in the lives of young people with an intellectual disability.

Canadian man John Cox (1989) articulated clearly the stigma of poverty from the perspective of a person with an intellectual disability.

> *Poverty to me means a lack of social standing. When you are poor you are looked down upon by society…. There is a stigma attached to being poor. You are forced onto “welfare” and can’t afford to take care of yourself. The very word “welfare” automatically means bum. People on social assistance are automatically poor. They live well below the poverty line. My cheque every month totals less than $700.00. That is nothing as far as living is concerned (p 11).*

Cox points out that the real impact of poverty can often mean a choice between food or medications. Furthermore, because paying rent often takes up such a significant portion of people's welfare payments they often resort to obtaining poorer quality housing. The link between poor quality housing and poor health outcomes is well established. Cox also brings up the issue of being penalised for working thus making it very hard for people to "get off" social assistance. Cox concludes that in order for people with an intellectual disability to become more financially independent social security benefits need to be in keeping with minimum wage standards.

Bewley (1996) provides an alternative explanation as to why people with an intellectual disability frequently are poor. Poverty in the lives of people with an intellectual disability is commonly attributed to a number of factors including: unemployment; reliance on benefits; or not owning property. In some circumstances, Bewley suggests, people with an intellectual disability have a significant amount of money paid out on their behalf to other people or organisations. Bewley gives the following examples: money for support being paid to services; money for mobility going into a shared or family car; money belonging to an individual being used to purchase "joint" items within a residential setting. She also goes on to discuss the impact on people with an intellectual disability having their finances controlled by other individuals who do not always look after it properly. Some people with an intellectual disability have their money managed by legal appointees if they are viewed as being "mentally incapable" of managing their own money. The appointee may have a different idea about appropriate management to the person with an intellectual disability themselves. Both misuse of funds by legal appointees and reluctance to approve spending have occurred in this system. Bewley stated:

> *People with learning difficulties are sometimes thought to be incapable of making, or being involved in, decisions about their money. We all have to learn to handle money and we all make mistakes but people with learning difficulties are often not given this chance. Even if someone cannot manage their money on their own, there are ways they can contribute to choices about how it is spent (p 11).*

Bewley suggests that research and education are necessary in order for people with an intellectual disability to experience greater choice and control over their own money and the way it is managed. She identifies the need for service organisations to develop clear guidelines for staff, in the area of assisting adults with an intellectual disability to manage their money. She also questions the appropriateness of trust funds solely administered by an accountant or solicitor (who may not even know the person with an intellectual disability). Furthermore, Bewley asks whether families are always the best people to manage their relative's money. These are all questions, which have a direct relationship to the issue of managing money and adults with an intellectual disability. However, in conducting this review we found that little research exists in the area of practical money management strategies and adults with an intellectual disability. While individualised funding can be seen as a powerful example of people with an intellectual disability having the opportunity to manage their own money (individualised funding is explored later in this review), few other alternatives were found during this review.

Summary

Despite increasing attention being paid to the issue of employment for adults with an intellectual disability, this group continues to experience disadvantage in the labour market. While some obtain full time employment, it is more common for people with an intellectual disability to be in part-time, low paid positions, or reliant solely on benefits throughout their lifetime. One obvious outcome of this situation is that adults with an intellectual disability continue to be at risk of poverty. A significant body of research consistently identified up to 60 percent of people with disabilities (including those with an intellectual disability) as living at or below the poverty line.

Women with disabilities have been reported as experiencing even greater disadvantage than men with disabilities in terms of income level. New Zealand research supports all of the above points.

People with an intellectual disability are increasingly voicing their dissatisfaction with their work situation and income level. In particular, the frequent experience of low wages has been commented upon.

The effects of inadequate income have been identified as generating poverty, ill health and impairment. Prolonged economic hardship has been reported as reducing physical and mental ability as well as impinging on routine activities of daily living. People with an intellectual disability living in poverty are less likely to access high quality services in the community – those who are in most need of services experience decreased access to them. People with an intellectual disability have commented on poverty and drawn attention to the stigma attached to this financial and social condition. Furthermore, the real implications of poverty such as being forced to make a choice between food or medication have been highlighted.

Factors such as unemployment, reliance on benefits, or lack of property ownership are not the only factors attributing to poverty. Some researchers suggest that people with an intellectual disability often have a significant amount of money paid out by other people on their behalf. In some cases the individual's entire income is managed by another person, who may not always manage the money in a way that benefits the person with a disability. In order to address this situation further research and education is required to enable people with an intellectual disability to have greater choice and control over their own money.

CHAPTER THREE

SUPPORTED EMPLOYMENT, INCOME AND ADULTS WITH AN INTELLECTUAL DISABILITY

A significant body of research has focussed on the relationship between supported employment and income. While supported employment has been explored in depth as part of the review on Work for adults with an intellectual disability, it is important to include some information here relating to how involvement in supported employment impacts on the income levels of adults with an intellectual disability. (This review will concentrate solely on the relationship between supported employment and income level. There is, however, some overlap in literature used in the two reviews). Research in this area appears to highlight two - seemingly contradictory - findings:

1. that supported employment models frequently deliver higher wage rates than do other models of employment
2. but that the potential benefits of these higher wage rates are often eliminated due to their interaction with the benefit/ income support system within which the country or region a person resides. This issue will be discussed in depth later in this review.

Mank, Cioffi and Yovanoff (1998) explored the issue of limited access to supported employment for adults with a severe intellectual disability and provided analyses of the employment features, support patterns, and outcomes for people with severe disabilities in supported employment. This study found that people with a more severe intellectual disability earn lower wages, experience a lower level of integration and have less typical features of employment. However, Mank et al also found that adults with a more severe intellectual disability who had better outcomes than their peers with a similar label were more likely to have positive relationships with their co-workers. Furthermore, these people were more likely to be in work settings where their co-workers had received training from supported employment personnel. People with an intellectual disability and high support needs are clearly disadvantaged in terms of their involvement in employment particularly in the area of wage level and are heavily over-represented in (very) part-time work. This results in a situation where people with an intellectual disability and high support needs are even more greatly disadvantaged in terms of income.

These same researchers (Mank, Cioffi and Yovanoff 1999) provide a report on positive relations of typical employment features and co-worker involvement with higher wage and integration outcomes for people with disabilities in supported employment. The focus of this research is in the area of natural supports, a concept which is defined by this group of researchers as “some kind of support or assistance in the workplace provided by unpaid co-workers or others to an employee with an intellectual disability”.

Data for this study were collected from thirteen vocational programmes providing employment services to persons with disabilities, in individual community jobs or small group placements, who were considered to be using natural supports. Data were analysed quantitatively using a multivariate analysis of covariance (MANCOVA) to test the relation between individual variables describing co-worker training, and multiple dependent variables measuring employment outcomes. Results of the study suggest that involving co-workers in supporting employees with disabilities has a positive impact on the wage level attained by the worker with a disability. The findings of this study provide strong support for continuing to develop supported employment and other similar employment initiatives for adults with an intellectual disability.

Rusch, Heal and Cimera (1997) examined a random sample of 197 supported employment employees with an intellectual disability in a longitudinal study. This study found that supported employees experienced more positive wage rates if they maintained their jobs over an extended period of time. Rusch et al contend that this finding highlights the importance of what they refer to as a "place-train-maintain" approach to competitive employment. Overall, it is clear that full time supported employment can achieve greater wage gains for people with an intellectual disability than other more traditional forms of employment for people with an intellectual disability such as sheltered workshops (see for example Revell, Wehman, Kregel, West and Rayfield 1994).

Thompson, Powers and Houchard (1992) investigated the effects of supported employment on wages earned by people with disabilities. In particular Thompson et al sought to determine whether supported employment produced higher wages than sheltered employment, and whether one model of supported employment had more impact than another. This group of researchers found that entry into supported employment is likely to produce higher wages than those achieved through sheltered employment. More specifically it was found that individual supported employment placements have positive effects on wage levels. Some of the increased wage effects reported in this study was generated through an increase in hours however more consistent and larger gains came from hourly rate increases. The results of this study are somewhat misleading however, as Thompson et al do not provide any analysis of how benefits and other entitlements are impacted on by the acquisition of paid work.

In a recent Canadian study Neufeldt, Sandys, Fuchs and Logan (1999) explored supported and self-directed employment support initiatives. The study examined the efficacy and benefit of supported and self-directed employment programs in four Canadian provinces. Both quantitative and qualitative methods were used to achieve the aims of this study. Both supported employment and self-directed employment refer to "person-centred" employment approaches, which typically focus on meeting the employment needs of one person at a time. Neufeldt et al define the practical meaning of both these terms.

Supported employment is based on the general principle that the inclusion of people with disabilities into the workforce is best achieved by assisting individuals to take up jobs that they have an interest in or aptitude for. Furthermore, training for specific jobs is considered to be more effective if it occurs in the actual work setting rather than in a "preparatory setting" such as a sheltered workshop. In the supported employment model individuals with disabilities are supported to obtain and maintain a competitive job with the help of a "job coach" who (in the best case scenario) is ultimately phased out of their role as the person with a disability becomes confident and capable in their employment role.

Self-directed employment. Self-directed employment is defined by Neufeldt et al as referring to a process by which disabled people are enabled to pursue entrepreneurial or small business options rather than wage employment. This term is not commonly used in relation to employment and people with disabilities (and rarely considered as an employment option for those with an intellectual disability). Neufeldt et al assert that self-directed employment has only emerged as an employment model for disabled people in Canada and other high-income countries during the 1990s although it has been the option of choice in many low-income countries for a much longer period.

Neufeldt et al conducted this research in two overlapping stages. Stage I used a person-centred case study approach to gather both quantitative and qualitative information from employment program participants and other informants from a number of relevant supported employment and self-directed employment agencies. Stage II explored the policy context of the provinces from which the samples were drawn in order to be able to identify policy issues relevant to each of the four Canadian provinces.

Descriptive information about the individuals who took part in this study identified that participants ranged in age, type of employment, hours and rates of pay. Their disability resulted from many different types of impairments including developmental disabilities (including cerebral palsy and Down syndrome), traumatic brain injury, epilepsy, hearing impairment, visual impairment, spinal cord injury, sensory impairment and others. Sixty individuals with disabilities took part in the study.

This study generated a great deal of valuable information relating to the views of people with disabilities towards supported employment and self-directed employment initiatives. First, supported employment initiatives were found to be more well established than self-directed employment schemes. Second, labour force participation and earnings were very low for people using both types of employment. Interestingly, despite the identification of the frequency of low wages and part time work, those involved in both supported employment and self-directed initiatives express a high level of satisfaction with their work, workplace and colleagues. Furthermore, programme leaders, job coaches and employers also viewed both types of programmes positively. Neufeldt et al contended that these personnel did in fact seem to ignore the reality of low incomes and part-time work and describe success in terms of personal growth (particularly for supported employees).

In considering these findings Neufeldt et al questioned why the model of service or the way services were offered were not revised with the goal of achieving higher income levels for those utilising supported or self-directed employment. Similarly to many studies in the area of employment and income for people with disabilities, Neufeldt et al found conclusive evidence that existing income support (benefit) systems tend to discourage people with disabilities (particularly those utilising supported employment) from earning at a level which could lead to a reduction in the amount of the financial support that they are currently receiving.

Steele (1996) articulated what she refers to as an “endemic dilemma” in the supported employment area. In summary, Steele highlighted the situation in the United Kingdom whereby funding for supported employment activities was increasing, staff were becoming highly skilled in assisting adults with an intellectual disability to gain employment, but the adults themselves were ineligible for paid work. Steele was specifically concerned about the situation for adults with an intellectual disability who use residential accommodation. This group of disability service users are unable to earn more than £15 per week or they lose funding for their accommodation. Steele contended there was a need to "face facts" in order for the principle of supported employment to progress. Steele believes that the very people that supported employment was designed to assist, those with high support needs, are suspended in a system which is based on the assumption that they are "unable to work".

> *This leaves hundreds of learning disabled people thinking that they are preparing for a paid job, hoping that their years in further education, training centres and employment projects will get them into the labour market. What they are really destined for is a group home which can only be paid for if they are unable to work (p 16*).

The negative interaction between income support and the transition to (usually part-time) employment is the issue which, in Steele's view, undermines the ability of adults with an intellectual disability to actually achieve the original aim of supported employment – real work for real pay.

Corden (1997) offers a similar perspective on supported employment and income for people with an intellectual disability. Corden conducted research designed to explore the relationship between supported employment and income in the United Kingdom. This two year study involved 22 employees who used supported employment services in the Liverpool area. Participants were interviewed prior to starting work, and after they had spent six months in the job. Information was also sought from carers, job trainers and employers. It quickly became clear that money was an important issue for those participating in this study.

Corden identified a number of problems or barriers for adults with an intellectual disability that she believes to be inherent within the supported employment model. Overidingly, it may be hard for an adult with an intellectual disability to earn a proper wage. This is due to the fact that this group may be disadvantaged in terms of the level of wages they can achieve in open, competitive employment. Furthermore, adults with an intellectual disability are frequently part of the low-paid sector, or are in part-time work. A lack of work experience may relegate them to the bottom of the pay scale, and then it may be difficult to move up the scale if they do not acquire a wide range of skills. Another significant barrier to achieving a satisfactory income level is created by restrictions on the number of hours that a person (who is dependent on income support) can work.

Further to this point, Corden contends that aiming toward a "proper wage" in line with the overall philosophy of supported employment may not be sensible in terms of the overall circumstances of adults with an intellectual disability. Attempting to maintain living standards while moving from out-of-work benefits to earnings boosted with in-work benefits **depends on being well informed**. Adults with an intellectual disability require a working knowledge of the social security system operating in their country or region, and the skills to make applications for appropriate benefits. Currently it is an inescapable fact that wages interact with benefits in a way that makes it hard for many people with an intellectual disability to increase their income by working. For some people whose arrangements for accommodation and care rely on the out-of-work benefits that they are paid, working for wages may force them to take a number of risks that it may seem more sensible to avoid.

Corden suggests a number of issues that should be considered pre-employment to ensure that adults with an intellectual disability are not financially disadvantaged by employment.

- To avoid losing entitlement to income support the interaction between social security provision, accommodation arrangements and paid work need to be carefully considered.

- Central to supported employment is the concept of “real work for real pay.” Corden cautions against “flexible” (low paid) employment designed to avoid loss of benefits. Such arrangements can also be perceived as exploitative.

- People with an intellectual disability need to be fully informed about the benefit system and the way it interacts with employment. Such information enables people to make informed choices about employment options.

- Advice about how to manage income may be necessary for some adults who have previously not managed their own money.

Corden concluded that further research is necessary to explore the interface between earnings and benefits.

Those involved with supported employment and other employment initiatives for adults with an intellectual disability frequently struggle with how to remunerate people appropriately for the work that they do. Zilber, Burnett and Castro (1993) describe the concept of productivity based wages and career structure in a small business model. They use an electronics company, which conducts electrical assembly work as an example of the implementation of this approach to determining an appropriate wage level for workers with disabilities. Zilber et al assert that productivity based pay is a feature common in the small business model. When applied to workers with disabilities the pay a person takes home should depend on two factors:

- what the work is worth (the typical wage a worker gets doing equivalent work in the industry
- the worker’s productivity (how many units per hour he or she makes in relation to the expected speed of a worker in industry).

Zilber et al conclude that the difficulty in this model is the establishment of a career structure which allows workers with disabilities to gain monetary awards for acquired competence. The electronics company used as an example by Zilber et al recognised that promotional opportunities were important to all workers but also found it difficult to find a realistic, fair and objective way of classifying workers across multiple attributes. In this case a system for classifying worker levels was derived from the functional competency model of Brown, Evans, Weed and Owen (1987). This model separates skills into three groups: core skills; extension skills; and enrichment skills. In brief, core skills refer to the basic skills essential for completing a given task. Extension skills are not essential but make a worker more effective and independent. Enrichment skills are broader skills, which make the worker socially appealing and thus more likely to be employable.

The electronics company decided to establish a promotional career structure, based on number of attainments in core and extension skills. Core and extension skills were classified as being basic or advanced. Workers were then rewarded financially according to whether they achieved basic or advanced ratings in each of the two skill areas. Despite describing this system of productivity wages Zilber et al gave no information regarding the impact of this system in real terms on the wages of workers with disabilities within this particular company.

Taylor (1996) discusses similar issues in a paper, which explores the implementation of supported employment in New Zealand. Taylor contends that:

> *For people with disability seeking employment the outcome has resulted in little, if any, change. That is because supported employment has been so tied into the traditional rehabilitative approach in its NZCFA articulation, people with disability still experience the same barriers to employment and employment support that they always have.*
>
> *Becoming more financially independent has also been problematic even though this is another clear goal of the Supported Employment programme from NZCFA. Perhaps, more correctly, the goal has been to get people off benefits which is assumed to be good for the individual as well as for the state (p 41-2).*

Taylor lists a number of issues that he sees as counter-productive to the goal of people with disabilities engaging in real work for real pay in line with the aims of supported employment. These issues include: the casualisation of the workforce (especially in entry level and lower skilled jobs that many people with an intellectual disability fill); part-time work and benefit abatement rates have meant that people who do not move entirely off benefits are disadvantaged. Taylor asserts that this has been disabling for those on benefits in the workforce with little support for those who do wish to participate in the workforce, the chances of actually coming off a benefit are small. In addition, the risk of stand-down periods are high thus making it difficult for people to be able to take up employment opportunities which may not work out in the long term. It is safer to choose to stay on a benefit than run the risk of being without an income if a job opportunity does not work out.

To conclude Taylor recommends that a number of strategies need to be adopted to ensure that supported employment is a positive option for those involved. Specifically, Taylor asserts that people should get paid for the work that they do as well as receive other benefits such as sick leave, annual leave, training and access to other staff benefits. Taylor also suggests some changes to payment and benefit abatement schemes and puts forward an alternative policy whereby a “performance wage” is paid to all those who work 15 hours per week or more. The performance wage would be based on an independent assessment of the supported employee’s contribution to the workplace compared with a theoretical industry norm. The employer would then pay that percentage towards the individual’s wage and the government contribute an amount to bring the total wage up to industry standard. The wage top-up is not new funding but comes from the individual’s base benefit. In this scheme any benefit remaining would be paid to the person as secondary income and other entitlements would remain the same until the usual thresholds were reached. The advantage to this system in Taylor’s view is that the supported employee would receive the same level of income as they would have received on a benefit, however the wage becomes the primary source of income. This would have the dual effect of maintaining a consistent level of income and of reducing the stigma of being on a benefit.

Reid and Bray (1997) provide important information relating to paid work and adults with an intellectual disability in New Zealand. This study included the views and experiences of adults with an intellectual disability in paid work. Selected disability agencies were asked to forward invitations to participate in this study to adults with an intellectual disability whom the agencies viewed as being successfully employed. Ten men and seven women participated in the study. Six people worked more than 30 hours per week, seven people worked between one-nine hours per week; two people worked between 10-19 hours per week and two people worked 20-29 hours per week. Those people who worked the fewest number of hours per week were likely to have their hours spread across several days rather than to work all their hours on one day.

The importance of paid work to adults with an intellectual disability was highlighted by this study with all those working expressing a strong desire to maintain their employment positions. However, only two of the participants in this study no longer needed the additional income support of a benefit. One participant articulated his desire to be benefit free.

> *…I'd prefer to be without the benefit really. Um I know it's going to be very hard but it's not easy for some people who's on disability… (p 93).*

Another participant who had been paid for odd jobs in the past explained the very real impact of the interaction between paid work and income support.

> *…Very little. Um it's how the benefit works… (p93).*

For only a small number of workers, being in paid work meant that they could achieve independence from the benefit system or buy their own home. All workers needed assistance to gain their employment position. Reid and Bray suggested that professional support staff are necessary in order to increase the numbers of adults with an intellectual disability to be paid workers and to achieve greater financial independence. Reid and Bray concluded with the following statement:

> *Currently, workers' expectations are often not being met because part-time work is limiting financially and career progression is not considered. These frequent limitations to minimal part-time work can mostly be attributed to staff practices that seem to be excessively concerned with avoiding any impact on state-provided income support. The provision of income support and operation of employment services must be urgently revisited, based on the knowledge that people with intellectual disabilities are not unemployable. They are motivated, able, and if appropriately supported, more than capable of contributing to the economy as taxpayers, rather than being dependent on it (p 95).*

Summary

This chapter on supported employment, income, and adults with an intellectual disability was included to reflect the relationship between supported employment initiatives and income level. As mentioned in the opening paragraph of this chapter, adults with an intellectual disability using supported employment typically experience higher hourly rates of pay than their peers who utilise more traditional vocational models.

Research has explored the characteristics or factors evident within the supported employment model, which have had a positive impact on hourly rates of pay. For example, people with an intellectual disability who are integrated and have positive relationships with their non-disabled co-workers are likely to receive higher wages. Furthermore, this type of positive work setting was likely to develop if co-workers have received training from supported employment personnel prior to and after a person with a disability entering the workplace. Linked to this is the finding that people with an intellectual disability experience higher wage rates if they are able to maintain their employment over an extended period.

The fact that supported employment is likely to return higher hourly rates of pay for adults with an intellectual disability must be considered alongside the somewhat contradictory finding that the financial advantage is not always **received.** The interaction between employment and benefits/income support frequently means that people with an intellectual disability find it difficult to achieve the goal “real work for real pay” that supported employment is based on. Many adults risk losing benefit entitlements if they attempt to make the transition from unemployment to employment. For many people with an intellectual disability (and others who may rely on an individual’s earning replacement benefits) the risk can be too great, making the transition to work insurmountable.

Chapter four of this review discusses the interface between work and income support in greater depth.

CHAPTER FOUR

INCOME, BENEFITS AND ADULTS WITH AN INTELLECTUAL DISABILITY

Almost fifteen years ago the Roeher Institute (1988) made the following statement within a report on the disability income system in Canada. This statement continues to have resonance for many adults with an intellectual disability in many different countries today.

> *Persons with a disability face barriers that often impede significant attachment to the paid labour force. As a result they must rely on programs of income support. Applicants and recipients experience a variety of problems in relation to these programs. These difficulties include, for example, the complexity of these programs, the requirements in the eligibility criteria, their discretionary features and their low level of benefit (p 113).*

As it has clearly been pointed out earlier in this review, adults with an intellectual disability commonly are recipients of benefits/income support. It is also clear that this reliance on benefits has a negative impact on their ability to generate a more favourable income level. A great deal of research exists which explores the interface between benefits and the lives and incomes of adults with an intellectual disability. Much of research in this area has been conducted in the United Kingdom, which has experienced restructuring and a great deal of legislative change during the 1980s and 1990s. The impact of such change on people with disabilities has increasingly been explored.

A review of the social security system, which began in 1984, resulted in legislative changes (principally the implementation of the Social Security Act 1996). However, benefits for people with disabilities were explicitly excluded from this review process with the government stating that they required more up to date information about the present effect of disablement and its effects. The Office of Population and Census Studies was subsequently commissioned to undertake a series of comprehensive surveys of people with disabilities and their income and expenditure patterns. In summary, these reports established that:

- 75 percent of disabled people relied on state benefits as their main source of income
- fewer than a third of those below retirement age were in employment
- and those working were likely to be in low-paid and part-time employment.

The Disability Working Allowance (DWA), a means-tested benefit intended to support people with disabilities in low-paid employment; and the Disability Living Allowance (DLA), a non-means tested allowance designed to contribute towards the "extra costs" of disability, were implemented in response to these findings (Noble, Platt, Smith and Daly 1997).

Noble, Platt, Smith and Daly conducted a three year study which focused on identifying the changes over time of the incidence of Disability Living Allowance in the low income population. Information for the study was collected from housing/council tax benefit data from local authority sources.

This research by Noble et al focused on the impact of the Disability Living Allowance benefit on the low-income population as a whole by measuring both the spread of benefits and their cumulative value to the area. They found that the DLA was bringing in large amounts of money to low income areas with high rates of disability. However, in response to this finding, Noble et al raise the question regarding the extent to which benefits can compensate for disability, and whether solely operating in terms of the medical model of disability is an effective solution to the multiple disadvantages experienced by people with disabilities. They suggest that the impact of benefits can only reach their potential, if they are accompanied by a social and environmental approach that can enable more equal participation by disabled people.

Hyde (2000) articulates a similar view during his detailed explanation of welfare restructuring in the United Kingdom during the 1990s. During this period both Conservative and Labour governments introduced initiatives with the aim of promoting labour force participation among disabled people. Hyde argues that while such initiatives were justified in terms of the reduction of poverty they were, in reality, driven by a perception of unsustainable fiscal pressures, and a belief that incentives in the social security system in the UK were responsible for undermining economic efficiency. Hyde also believes that the notion of citizenship, legitimated the shift of moral responsibility for needs satisfaction away from the state and onto the individual

An alternative approach to welfare reform is suggested by Hyde. Hyde is of the view that whilst a radical overhaul of the disability benefits system in order to ensure a comprehensive disability income is an important anti-poverty strategy, such a strategy must be accompanied by policies to promote full access to the labour market. Hyde draws on the work of Oliver and Barnes (1998) who identify a number of factors critical to include in the United Kingdom welfare reform agenda. These include:

- a stronger approach to civil rights which would cover all employers, contain fewer grounds for exemption, and involve penalties for employers who discriminate

- employment equity, where employers are legally obliged to adapt premises and equipment so that they are suitable for disabled workers. This would be enforced through contract compliance whereby firms which failed to make the necessary adaptations would lose the right to bid for government contracts

- a tougher quota system whereby employers are required to include people with disabilities as employees

- an inclusive education system which provides people with disabilities the skills necessary for the attainment of satisfactory employment.

As it was asserted earlier, a significant body of research produced in the United Kingdom explores the issues associated with social security benefits for adults with an intellectual disability. Simons (1998) described the current system as anomalous, complex, unreliable and lacking in coherence.

> *It hinges around the notion of incapacity, which fails to take account of the wider social context (including job availability or in-work support). People with*

> *learning difficulties are vulnerable to either being classed as incapable of work (and treated as low priority for employment services assistance) or being judged as fit for work (and facing what may be inappropriate sanctions)(p 4).*

British research is very concerned with how the number of hours a person with a disability works each week, has the potential to greatly (and often negatively) impact on that person's income. Simons contended that once people are established on incapacity benefits the transition to work can be difficult. Going beyond the arbitrary 16 hours per week cut off point is simply too risky for most people with learning difficulties, while working less than 16 hours per week inevitably means that any increase in income is limited to £15 per week. Simons also articulated the unhelpful link between housing costs and social security benefits. It is clear that where a person with an intellectual disability lives can determine whether they can **afford** to work: those still living in the family home tend to be the most likely to take up supported employment. For those living in their own homes, the restrictions on housing benefits adds to the difficulties of moving into paid work. But the biggest unemployment trap is experienced by people in residential care, whose social security benefits are almost totally used up to meet the costs associated with living in residential accommodation.

Simons provided a number of suggestions which, in his view, would ensure that people with an intellectual disability are not adversely affected by reforms to the welfare system. In particular changes to the social policy framework need to be designed and implemented in a way that:

- promotes inclusion
- promotes self-determination
- offers security to vulnerable people
- makes efficient use of resources.

With particular reference to social security benefits, Simons asserted that the national minimum wage should be inclusive but remain flexible enough to support those who are less productive by allowing the combination of wages and benefits to the minimum wage level. The concept of incapacity, in Simons view, should be replaced with a system that assesses disadvantage in the labour market, does not discourage people from starting work, or penalise people for limited earning capacity, and offers security if a job does not work out. Furthermore, it is suggested that a single income maintenance benefit, in which all incapacity benefits and in-work benefits could be merged into one system, would simplify the system and ease the transition into work.

Similarly, Steele (1997) assessed the impact of the Disability Working Allowance on employees with disabilities by describing the actual situation as experienced by a woman with a disability. The Disability Working Allowance is only paid when a disabled employee has a contract for 16 or more hours per week. Steele's view is that fewer companies currently adopt full time contracts therefore disabled people will not be able to work unless they are offered 16 or more hours per week. Steele tells Hazel's story. Hazel (a woman with a physical disability) was committed to finding work and eventually did so with a home shopping company. The difficulties that Hazel encountered in beginning work with the company were the result of the general recruitment policies employed by this company and many other companies existing in today's competitive market. The common practice of operating a "flexible workforce", whereby employees are only guaranteed by contract a limited number of hours per week (usually somewhere between 8-15), is prohibitive for people with disabilities. As Steele pointed out entry into the labour force for a person with a disability inevitably means giving up the security of welfare benefits, yet (in the U.K.) employment incentive schemes are not triggered by less than 16 hours work per week. Steele clearly illustrated the impact on the level of income a person with a disability would receive if they worked fifteen hours a week as opposed to sixteen hours per week. Hazel's income made up solely of benefits was £78.70 per week. If she received a contract for 16 hours work per week she received a total income of £120.84, however a contract for fifteen hours per week reduced her weekly income to £46.45 per week. This loss in income is a result of Hazel's ineligibility for the Disability Working Allowance and Access to Work Allowance. The financial disadvantage of taking up an employment contract which provided less than 16 hours work per week is significant.

The impact of an earnings cap is outlined in an article by Holman (1999). The article focuses on the appointment of a person with an intellectual disability onto the Board of Directors of a not-for-profit organisation, which provides intellectual disability services. Douglas Armstrong, a man with an intellectual disability was successful in securing this nationally advertised position. He is expected to contribute to decision-making and other activities associated with running the Trust in the same manner as other Directors. His job is currently part-time with him currently spending two days per week working for the Trust. For this he receives £14.74 per week despite the fact he is paid at the same rate as other Directors. The reason for this is that regardless of his position, Douglas is caught in the "residential care trap" whereby earnings are redirected to contribute toward living costs. The movement toward appointing people with an intellectual disability to positions in which they can influence how services are delivered is clearly a positive one. However, the issue of benefit related earnings caps must be resolved if adults with an intellectual disability are to feel any real incentive to work, or to feel secure about making employment related decisions.

Holman (1997) comments on the financing of support services and benefits. He uses the example of people with an intellectual disability effectively being forced to live in group homes, when many would prefer to live alone with people of their choice.

> *The financing of these homes has depended on people claiming a care allowance the people living in them do not see. It met budget shortfalls rather than offered a better quality of life. One consequence of such a philosophy has been the placing of people in impossible benefit traps that effectively disenfranchise them from working. It traps individuals in a life of poverty that has been further eroded at every opportunity (p 4).*

Furthermore, Holman contends that people with an intellectual disability are yet to be fully included in the implementation of direct payments legislation. He is particularly concerned that many people with an intellectual disability will be excluded from direct payments due to a clause in the legislation that requires that those receiving direct payments must be able to "legally give consent." Holman advocates for a system of representation for those who are unable to speak for themselves but who may receive a better quality of service through direct payments.

People with an intellectual disability themselves are increasingly voicing their perspectives and views relating to the impact of ever-changing benefit systems on their ability to work, and maintain an acceptable standard of living. The issue of the benefit system representing a disincentive to work is taken up by Simone Aspis, a disability activist and woman with an intellectual disability herself. In particular, she comments on the Welfare Reform and Pensions Bill recently introduced in Britain. It is Aspis' view that this Bill increases the discrimination currently experienced by people with an intellectual disability by cutting benefits and increasing the stigma attached to receiving a benefit. Additionally, changes to the benefit system would result in a lower disposable income for many people with an intellectual disability, according to Aspis, who pointed out that a lower disposable income can affect a person's level of personal autonomy, not just their ability to pay bills and live independently.

The introduction of the national minimum wage in the United Kingdom has been comprehensively explored by disability researchers. Mencap (Berry 1999) conducted a study, which estimated that a total of 1000 people had lost their part time jobs or had their hours cut as a result of the introduction of the National Minimum Wage legislation (NMW). Mencap supported (and continues to support) the introduction of the national minimum wage, as this organisation sees the NMW as having the potential to bring a long overdue rise in wages for people with an intellectual disability. A significant rise in wages can lead to a significant improvement in the quality of life able to be achieved by this group. The Mencap survey however uncovered some adverse consequences of the minimum wage legislation and articulated these in the 1999 report.

People with an intellectual disability and high support needs, were found to be particularly affected by the introduction of the minimum wage. It is common that this group of employees contribute to the workplace socially rather than only in a commercial manner. People with high support needs (severe intellectual disability) derive significant benefit from participating in the workplace and interacting with other people. Before the introduction of the national minimum wage in Britain there were many examples of people with high support needs in informal arrangements in which they performed some basic tasks and were given a small payment for their contribution (usually at the level of £15 per week – the amount that can be earned before Income Support is altered). The minimum wage legislation defines people with disabilities in this position as employees, even if their output is low and they do not have a formal contract. The effect of the legislation on these kinds of arrangements has included the following outcomes:

- people have been dismissed because the employer is unwilling or unable to pay the minimum wage
- people continue to receive payment which is below the minimum wage (in breach of the minimum wage legislation)
- people's paid hours have been reduced so that the level of pay is at the national minimum wage rate (which also constitutes a breach of the minimum wage legislation)
- employers have been unable to employ people with an intellectual disability on a trial basis.

Berry reports that Mencap's position is that those people with an intellectual disability and high support needs who are involved in the workplace, should not have their activity defined as work. Instead, these positions should be referred to as special placements so as not to be affected by minimum wage legislation. Mencap believes this could be achieved by an addition of a new section to the statutory guidelines for the national minimum wage. This section would outline who would be eligible for these arrangements (that is, people whose output is too low to enable them access to Supported Employment) and put in place mechanisms to ensure that special placements cannot be abused by employers.

The Mencap survey also explored the relationship between the National Minimum Wage legislation and supported employment. Berry contends that there is clear evidence that if an employer considers the output of a person with an intellectual disability to be below that of a non-disabled worker, they are disinclined to pay the national minimum wage or employ them within the open job market. However, many employers will consider employing people with an intellectual disability through supported employment schemes. Supported employment is a very attractive option for employers in the United Kingdom as they only pay a percentage of the wage that represents the level of the employee's output (ie, if a person is deemed to reach 45 percent of the output of a non-disabled worker the employer will pay 45 percent of the wage) with the remainder being paid by government subsidy. The employee gets the full wage for the job (the national minimum wage or higher).

Minimum wage legislation has led to an increase in the demand for supported employment as employers seek subsidies for the wages of people whose output is lower than others. This has led in the U.K. to significant pressure being put on the scheme. The most significant implication of this for people with an intellectual disability, has been the lack of available supported employment places nationally, with provision across the country being inconsistent. This means that people of similar output level will receive different levels of subsidy from the scheme, and in some cases someone might get a subsidy in one part of the country but not another. Because of the competition for supported employment placements, people rarely leave a supported employment scheme, therefore fewer and fewer people are getting access to it for the first time. Another problem is the withdrawal of supported employment support before it is appropriate, which can often result in people with an intellectual disability losing their jobs if their employer refuses to absorb the extra costs associated, related to wages or support for the worker with an intellectual disability. One issue related to the use of supported employment schemes is directly relevant to the issue of income level. If a worker with an intellectual disability is involved in employment which generates a relatively high wage (for example labouring) supported employment schemes will often not commit to the higher costs associated with subsidising a higher wage level. This represents a structural barrier to adults with an intellectual disability achieving a higher level of income than is commonly expected for them to achieve – that is, people remain caught in the poverty trap

The impact of a National Minimum Wage on disabled people in the United Kingdom was also explored by Schneider, Simons and Everatt (2001). The National Minimum Wage was introduced in 1999 and covers workers who are 18 or over, and who are working under a contract of employment or other form of worker's contract. This includes part-time and agency employees. People with disabilities are not exempt from the National Minimum Wage. Because people with disabilities commonly receive low rates of pay there was an assumption that a high number of disabled people would benefit from this new legislation. Schneider et al were interested in investigating the impact of the NMW and in particular how it was affected by: age; gender; impairment; the pay groups that the person was in prior to the implementation of the NMW; and the type of agency in which (or through which) they were employed.

A survey was conducted approximately 4-5 months after the introduction of the NMW legislation. The data analysed for the study were collected from 63 agencies who gave information relating to 1,107 individuals working in various settings including: supported employment; vocational rehabilitation; sheltered workshop; supported placement scheme; day centre; social firm/operative. The overall response rate to this survey was 6 percent (this is an extremely low response rate to be reported in a piece of published research). Schneider et al attributed this low response rate to the fact that it was an unsolicited postal questionnaire. They also felt the low staffing level of most agencies is a barrier to the completion of a complex questionnaire such as that used in this study.

The majority of people surveyed (78%) had an intellectual disability. Consistent with most employment related research, only 37 percent of employees were female compared with 63 percent of males. Ninety-six percent of employees were classed as "White" by the respondent responsible for completing the questionnaire. Schneider et al identified four pay groups during the process of analysing the data:
Group 1 – those people who were not paid before April 1 1999 (23%). Many of this group had been engaged in work experience; Group 2 – those people who earned less than £3.60 and whose total earnings amounted to £15 or less (probably because they did not want to affect their benefit entitlement) (26%); Group 3 – The remaining people whose pay was below £3.60 prior to the introduction of the NMW (15%); Group 4 – those people whose pay was equal to or greater than £3.60 prior to the introduction of the NMW (36%).

Schneider et al reported the following findings. Overall they found that younger people with disabilities were more likely to benefit in real terms from the introduction of the NMW. After analysing the mean hours worked and levels of pay before and after the NMW Schneider et al identified that unpaid hours increased, paid hours decreased, pay per hour increased, and weekly take home pay increased despite the decrease in paid hours for this group. When considering the factor of gender they reported that even prior to the introduction of the NMW there were marked gender disparities in the surveyed population. For example, women were disproportionately represented in the unpaid group and women worked fewer paid hours than men (resulting in less take-home pay). After the introduction of the NMW the decline in paid hours was more significant for men than women (who generally worked fewer paid hours), increase in pay per hour was significant for both sexes but more so for men, and men **but not women** took home more money after the introduction of the NMW. An increase in unpaid hours and decrease in paid hours was experienced by people with an intellectual disability and (to a lesser extent) people with mental illness **and not by other disability groups**. The result of this was that people with an intellectual disability or mental illness **did not** experience an increase in their take home pay.

The question "who gains from the NMW?" was central to this study. This study included the experiences of people with intellectual, physical and sensory disabilities, and mental illness. Schneider et al reported that people with an intellectual disability were more likely to be in supported employment than people with any other impairment and although their hourly rate increased, their average take home pay did not increase correspondingly. This was because it was clear that their work schedules were adjusted to control for the effects of the NMW. It is not clear that people with an intellectual disability had any real control over this process nor whether the changes were designed to protect the benefit derived income that a person with an intellectual disability may be already receiving, or to ensure that an employer would not be obliged to pay more for the services of an employee with an intellectual disability.

Andrew Holman (2000) also highlighted the diverse impacts of the introduction of the National Minimum Wage on adults with an intellectual disability. Holman details the experiences of two employees with an intellectual disability. Alan had worked for his local vet's practice since a successful work experience three years earlier. His job was created for him as he was seen as having valuable skills to contribute to the practice. He was paid at a rate of £1.50 per hour. His hourly rate was adjusted to the level of the National Minimum Wage (£3.60) just prior to the introduction of the legislation. Conversely, Tom, who worked one day a week in his local council offices was made redundant prior to the introduction to the National Minimum Wage. He had been paid £1 per hour.

The financial implications of half- and full time employment for people with disabilities have also been examined for some time. Schloss, Wolf and Schloss (1987) conducted a study which utilised a balance sheet approach to explore three income levels: no earned income; income from a part-time job (20 hours); and income from a full time job (40 hours). This research suggested that net disposable income was comparable for individuals working part time when compared to those individuals working full time thus in the view of Schloss et al, a financial disincentive to seek employment. Those in part time employment received benefits and allowances (including medical insurance) while those in full time employment did not. A full time wage commonly earned by a person with a disability did not exceed the benefits and allowances entitled to those working part time.

In order to provide information relevant to the New Zealand context a short interview was held with a supported employment professional This person was asked about the interaction between supported employment and benefits for New Zealand adults with an intellectual disability.

Similarly to research reported in other countries, New Zealand adults on benefits have their income restricted by an earnings cap This cap was recently set at $100, a figure that compares favourably with earnings caps experienced by those receiving benefits in other countries. Adults in this country are usually eligible for an accommodation supplement. It is this supplement that is reduced, or in some cases stopped completely when an adult enters work. While U.K. researchers contend that a person needs to work more than 16 hours per week in order to benefit financially from employment, the professional consulted for the purposes of this review estimated that 10 hours was the threshold for (most) employment situations to be financially beneficial

All workers involved in the supported employment service consulted for the purposes of this review earn the New Zealand minimum hourly rate ($8.70). It is common for supported employees to have their wages subsidised. Employers in this country can claim up to 70 percent of a supported employee's wage for a period of up to one year. When asked about the barriers associated with employment and benefits, the supported employment professional consulted perceived the obligation to pay secondary tax on earnings achieved in combination with income support was one of the biggest disadvantages for adults with an intellectual disability.

Summary

The fact that most people with an intellectual disability rely on income support to meet the costs of everyday life is currently inescapable. As a result, a great deal of research has explored the impact of various forms of legislation. Such legislation has usually been designed to improve access to employment, and to achieve more favourable income levels for people with disabilities.

Some researchers have suggested upon evaluating the beneficial effects introducing such benefits are diluted, if they are not accompanied by a social and environmental approach that can enable more equal participation by disabled people. Other researchers have gone so far as to question the intent of these initiatives, saying that instead of being about the reduction of poverty, they were actually driven by a perception that incentives in the social security system were responsible for undermining economic efficiency. That is, people were choosing not to work because they received income support to a level that made that a viable option.

Current thinking promotes the need to ensure a comprehensive disability income in order to minimise the risk of poverty. Coupled with this, however, is the need to promote full access to the labour market. Another barrier to increasing income level is where a person lives. It is clear that where a person lives can determine whether a person can afford to work. Those still living at home tend to be the most likely and able to take up supported employment. Contrary to this those living in residential care are the most likely to be unemployed with little or no disposable income. Their income is almost entirely used up to meet the costs associated with residential accommodation.

New Zealand adults in supported employment, and who also receive income support, also experience barriers to increasing their income level. New Zealand adults are subject to an earning cap which restricts their earning potential (although the earnings cap in this country appears more generous than, for example, the UK. There is also a risk of losing benefit entitlements, in particular, the accommodation supplement which is often the first affected by transition from unemployment to paid work (even part-time). Another significant barrier for New Zealand adults is the obligation to pay secondary tax on earnings achieved in combination with income support.

CHAPTER FIVE

INDIVIDUALISED FUNDING

Interest in individualised funding or direct payment (as this model of funding is referred to in the British context) has increased during the past 25 years, and various forms of individualised funding now operate in many countries (Dowson and Salisbury 2000). This funding model originated in the physical disability field but is now increasingly being implemented within the field of intellectual disability.

Individualised funding refers to a process whereby people with an intellectual disability receive monetary entitlements, and have the opportunity to use those entitlements to purchase supports and/or services of their choice. This model is intended to afford people with an intellectual disability greater autonomy and personal independence, through being able to create support configurations which best suit **their own** needs.

For some people, the concept of individualised funding is linked, inextricably, with the notion of self-determination. Individualised funding is seen as an integral step to achieving self-determination. Individualised budgets can be a way of achieving both economic efficiency, and a personal future that matches a person's unique needs (New Hampshire Self Determination Project 1995).

The New Hampshire Self Determination Project details a vision for creating a community to support all people, including those with disabilities. Central to this vision is a desire to see widespread implementation of individualised funding for people with disabilities.

The following statement illustrates how the notion of self determination is underpinned by a need for individuals with disabilities to be able to control their own money.

> *The development of an individual budget based on the unique supports that an individual may need is a first and necessary step toward self determination. The right to free association is fundamental to the concept of determining where and with whom one lives, plays and works. Currently many people in the system lack the basic freedom associated with self-determination precisely because their budgets are intimately tied to those of other individuals within a total budget. Traditional agency rate setting is grounded in the congregation of persons with disabilities, determining agency costs and allocating the amount thus determined with the full expectation that all dollars will be spent. This results in fiscal co-dependency, which is a major barrier to self-determination. Individual budgets allow for free movement and free association (p 21).*

The seriousness with which individualised funding is now treated internationally is illustrated by the outcomes of the First International Conference on Self-Determination and Individual Funding, which was held in July 2000 in Seattle, U.S.A. As a result of this conference Dowson and Salisbury (2000) produced a comprehensive report which provides important information relating to the development of individualised funding as an alternative model of funding, and provides a blueprint or way forward for individualised funding initiatives in the future. The individualised funding blueprint is based on work conducted within conference by the 1,250 delegates (representing 23 different countries) who attended this event.

The conference was focussed on practical outcomes and the report identified that a number of factors about the individualised funding need to be accepted if it is to be accepted as a viable alternative to other more traditional funding models. These factors include:

- individualised funding represents an investment by society in people and communities. People are able to move from being "clients" to being "citizens"

- individualised funding is based on the strengths and abilities of people with disabilities to identify their own needs and how they are best met. It is therefore reliant on mutual trust and partnership between those requesting and receiving individualised funds and those allocating the funding

- people using individualised funding must be free to use their funds across jurisdictions and service, providing for a process of negotiation between the individual and holder of public funds (p 40-1).

The Roeher Institute (1993) describe individualised funding as "representing a shift from supply-side funding to demand-side funding". The Roeher Institute provided the following definition for the term individualised funding.

> *Individualised funding arose within this ferment in the social welfare field. It is an arrangement that seeks to promote self-determination by maximizing individual choice. Individualised funding also promotes the recognition of individual differences. In fact, it is predicated on the assumption that each person is unique and requires a different set of responses to personal circumstances. Finally, it seeks to achieve equality by helping to redress inadequacies in the goods and services to which persons with disabilities have access. Individualised funding may first appear to be a relatively obscure and complicated process that has relevance to only a small part of the population. In fact, it is a variation of current funding arrangements and its potential for application to other service areas is enormous (p 7).*

The Roeher Institute contend that individualised funding refers to a process by which people with disabilities receive money directly which enables them to meet their basic and disability related needs. Basic needs are defined as food, clothing, shelter and utilities. Disability related needs are defined as medications, equipment or personal or attendant services. The individualised funding system involves the transfer of money directly to individuals on the basis of an assessment that identifies an individual's needs, and the cost of providing for such needs. The person with a disability is then able to purchase the goods and services of their choice to meet the specified needs. Individualised funding provides people with disabilities the opportunity to take their funding elsewhere if they are dissatisfied with the quality of service that they are being provided with.

> *Individualised funding is different from welfare. It represents a vision which, in fact, moves beyond existing welfare systems. Under individualised funding,*

> *dollars are transferred to consumers not only for basic needs but also for disability related needs. In fact, the distinction between welfare and individualised funding goes beyond the simple transfer of dollars. Welfare systems do not involve consumers in making service choices that affect their quality of life. Individualised funding represents a shift of control in that consumers play a key role in needs assessment. They are actively involved identifying their needs and determining the most appropriate way of meeting those needs. Furthermore, individualised funding allows them to become consumers of services rather than recipients of services. They buy services rather than have them purchased on their behalf. In some models of individualised funding, consumers actually become employers who recruit, hire, train and supervise service providers (The Roeher Institute 1993: p 16).*

The Roeher Institute asserted that in order for individualised funding to work effectively, the person with a disability frequently requires additional support. These supports are usually personal networks, brokerage or consulting services and other services which fulfil a monitoring role. Personal networks are usually comprised of family and friends who support people with disabilities who are accessing individualised funding to make decisions. People with disabilities sometimes hire brokers who provide advice and consultation relating to the purchase of supports and services. The Roeher Institute identified that brokers usually fulfil the following roles:

- provision of information
- liaison with consumers and their personal networks
- clarification of individual needs and expectations
- location of community resources to meet identified needs
- development of service plans
- monitoring and evaluation
- liaison with service providers and government representatives
- problem resolution
- stimulation of service development.

Several models of brokerage services have developed in response to the demand for individualised funding. In the Canadian context the Roeher Institute outline the basic principles of five different approaches to brokerage:

Agency brokerage: This model of brokerage involves staff members of disability agencies taking the role of broker. Developing individual service plans, negotiating for funds to meet consumers' needs, and implementing and monitoring plans are all tasks associated with this model of brokerage. Agency brokerage can become problematic, if people with disabilities use support services provided by the agency that hires the brokers. This can mean that brokers are required to act as independent advocates against their own employers and can, as a result, compromise their ability to act in the best interests of their clients - people with disabilities.

Independent service brokerage: Independent service brokerage was developed in response to the aforementioned problem. In this model, brokers are not linked with a service provision agency but are usually paid by an independent board of directors.

Freelance brokerage: Freelance brokerage was also developed to avert conflict of interest situations for brokers. Freelance brokers are hired by individuals with disabilities to assist them to develop service plans and to gain individualised funding. This model is relatively rare in the Canadian context as there is a lack of funding to support this model.

Placement brokerage: Placement brokerage was designed to assist with deinstitutionalisation, whereby an existing residential staff member would assist people with disabilities to organise the supports necessary to live within community based settings.

Government brokerage: Unlike the previous models of brokerage, government brokerage is not driven by consumer demands to the same extent. Under this model government officials manage client coordination or case management by assessing consumer needs, devising a plan and negotiating with community agencies. It is also common for government brokers to play a monitoring role. This model can also produce conflict of interest situations due to the fact that the same body is responsible for both assessing client need and providing funding to meet those needs.

The issue of brokerage continues to be debated in discussions relating to individualised funding. It has recently been reported that in the U.S.A. up to 80 percent of planning for individuals receiving individualised funding is conducted by professionals who frequently call themselves brokers (Dowson and Salisbury 2000). Many of these brokers work either for government or service providers. While some people believe successful brokerage can occur within this context, others believe that a significant and problematic conflict of interest is presented for the broker. This conflict of interest has the potential to impact negatively on the person with a disability, particularly if the broker is under pressure to adopt a gate-keeping or rationing role (Dowson and Salisbury 2000).

The issue of brokerage was explored in depth at the Seattle Conference. Brokerage was described as both a system function and a technical support process that can:

- provide advice and information
- assist in reviewing and clarifying lifestyle needs/expectations
- develop and review personal plans
- negotiate individualised funding
- locate, arrange, monitor, and evaluate community services and resources
- resolve and mediate problems
- modify existing services or help stimulate new ones (Dowson and Salisbury: p 60).

The role of the individualised funding broker, is diverse and requires specific skills. The question remains – if a broker must be independent from both funders and service providers, who then pays for this necessary service. Three possible brokerage models were put forward:

1. a community based, not-for-profit organisation controlled by consumers or with strong consumer representation, that contracts with government to provide brokerage services for a specified number of people. This model was identified as having the potential to undermine consumer choice because an agency employs and supervises the brokers

2. funding for planning is attached to a person's approved plan and budget. Planning supports can then be purchased for a fee from planning professionals (brokers). Although allowing personal choice for the individual, this model was critiqued for its free-market philosophy, which could create a risk to planning quality and individual autonomy

3. a mixed model where core funding would be paid via contract to either a consumer controlled non-profit organisation, or a profit company to provide core services including: access to information; staff who could respond to initial consumer needs; and a list of independent brokers. The positive attribute of this model was that it facilitates the development and implementation of a planning infrastructure at the community level by: providing regulatory oversight; reducing the risk of brokerage becoming bureaucratic; maximising choice and flexibility; addressing agency training and community development needs.

Monitoring is another area important to consider when thinking about individualised funding. The Roeher Institute outline a number of different ways of implementing monitoring of individualised funding arrangements. Sometimes people with disabilities themselves who have experienced individualised funding, fulfil the monitoring role for other individuals. It is also common for monitoring to be conducted by brokers, or other community agencies specifically designated to this role.

The Roeher Institute study provides relevant information relating to the implications of adopting individualised funding as a model for meeting the needs of people with disabilities. In particular, they outline the potential **benefits** of individualised funding, and the limitations of this model. Such benefits include:

Access: Greater access to services is one significant benefit of the implementation of individualised funding. A lack of support services is a common problem for people with disabilities in almost all communities. Individualised funding is underpinned by the notion that transferring money directly to individuals will not only allow them to choose to purchase services within the existing pool of services, but will also serve to generate the development of new services. If individuals with disabilities need supports that are not currently available they will be able to generate the provision of these services by having the money to purchase what they want. Further to this point, is the flexibility that individualised funding has the potential to generate. Supports and services need to be open to change in order to meet the diverse needs of clients with disabilities. Individualised funding enables people with disabilities to create supports that meet their specific needs, and reduces the likelihood that they will be forced to use services that are not appropriate to their individual circumstances.

Eligibility: Individualised funding has the potential to reduce some of the issues associated with eligibility that are frequently encountered by people with disabilities. Eligibility criteria are inherent to the provision of disability related services and often involve people having to qualify for services on the basis of factors such as (for example) age, cause of disability or level of income. Within the traditional funding model individuals are assessed by professionals to identify their needs and then those needs usually are met within the parameters of the services they deliver, or the services that are currently available. If an individualised funding model is implemented individuals are significantly involved in identifying their own needs and the best way for those needs to be met – including the most appropriate way for the support to be delivered.

Responsiveness: Traditional funding models have been criticised for delivering services that are driven more by the needs of the service than by the needs of the individuals who use such services. In the area of personal supports for example, people with disabilities themselves have had little say as to the type of services available, how and when services are delivered, and by whom. Individualised funding offers the potential for people with disabilities to have their **specific** support requirements met rather than having to make do with the services currently available. Furthermore, as individuals are purchasing their own services with their own money, they will experience a greater ability to determine **how** services are delivered to them. The development of relationships with support workers that facilitate the delivery of support in a manner that is determined by the person with a disability, ensures a greater quality of support.

Empowerment: One important outcome of individualised funding arrangements is the increased opportunities for self-determination. Recipients of individualised funding have the opportunity to interact with their support workers in a way previously denied to them. They are able to hire, train, and potentially fire staff according to their own needs. This level of personal autonomy has not traditionally been available to people with disabilities.

The Roeher Institute study also identified some of the **limitations** of this approach. One problem with individualised funding can be attributed to an over-reliance on the demand-supply argument. That is, while in theory it may be possible for new services to be generated through giving people with disabilities the means to purchase services, the reality is that people with disabilities may be forced to continue to purchase existing services because they are the only services available to them. Community-based housing arrangements that provide personal supports are often scarce; a person may be forced to purchase a bed in a group home because that is the only option available. This situation may not lead to an improvement in the quality of life or personal autonomy that person is able to achieve. The Roeher Institute suggest that the demand-supply argument may be more relevant when people with disabilities are using individualised funding to purchase personal assistance (particularly when staff do not require formal qualifications). New and creative supports and services do not magically appear in response to individualised funding. Individualised funding models need to be accompanied by comprehensive investments in community development, and particularly development that is responsive to the needs of people with disabilities themselves.

The discretionary nature of individualised funding has also been considered to be a limitation of this approach. "Individualised funding can give way to wide disparities in the way individuals are treated." (p 58). Research focusing on individualised funding has consistently highlighted this point. Two people with similar needs may receive very different types and amounts of assistance depending on how articulate they are, or how well a broker advocates on their behalf. Those individuals who are not so able to communicate their needs, or who do not have access to personal networks or funding brokers may be disadvantaged. The Roeher Institute suggest that new models for deciding levels of funding are required, that ensure equity but at the same time allow for flexibility of support and individualisation of costs associated with providing support.

People with disabilities who enter into individualised funding arrangements may experience a new level of control over their services but also a greater level of personal responsibility. While some people with disabilities are entirely comfortable with the process of "becoming an employer" for other people, the process of hiring, training and supervising personal supports (including handling the administrative tasks associated with being an employer) can be a difficult and time-consuming task. Some people with disabilities who participated in the Roeher Institute study said that they did not want the management of personal supports to become a full time job because they believed that this situation would result in further marginalisation – they did not want to spend all their time and energy on coordinating their own supports.

Systematically imposed limitations are identified by the Roeher Institute as including resource limits and skewed needs identification. The way that individualised funding is allocated is varied between countries, regions and services. For instance, some providers may impose a limit on the amount of support any one individual can receive. In other cases the type and amount of service an individual can expect to receive is based on available funding rather than on need.

Other limitations were identified in this study, as those created by restrictions on the type of services that people with disabilities are able to purchase with individualised funding. One controversial issue that continues to be at the heart of all debate surrounding individualised funding, is that of payment of relatives who provide personal support to people with disabilities. On one hand, it is acknowledged that family often provide personal support that, if not provided by them, would have to be provided by paid workers. Furthermore, families often provide support at considerable personal and financial cost to themselves. On the other hand, funders argue that there would be no mechanism for controlling costs if they allowed families to be the recipients of individualised funding.

Dowson and Salisbury (2000) also explore the issue of payment to family members. They present the argument over this issue in the following way. Those that support family payments argue that:

- if family do not provide support then it would still have to be provided by someone else at public expense
- family members who provide support may have to give up their own employment, thus the whole household is reduced to poverty
- people with disabilities **may** prefer support from members of their own family and this preference should be respected.

The main arguments against payments to family members are:

1. government agreement that family members are entitled to payment for looking after family members could result in an uncontrollable drain on public funds
2. and if family members received payment they would have a vested interest in the life choices of the person with a disability (which could lead to exploitation).

These inherent conflicts relating to family payments can be addressed, according to Dowson and Salisbury, through the processes of planning, funding and support delivery. It is their view that strong individualised funding systems should be designed to minimise conflicts, but where they do exist they should be bought out in the open. They also contend that the individual's funding plan is intended to be a statement of the individual's wishes and provides a check against the imposition of other people's choices. Those with a vested interest should not be involved in the development of a plan, and if a person needs assistance it may be most appropriately provided by a broker. Finally, the arrangements for support that a person with disabilities is using can be examined to see to what extent they support self-determination. Dowson and Salisbury suggest that these processes can be applied to situations where support is provided by family members.

Dowson and Salisbury conclude with the following statement.

> *Possible conflicts of interest resulting from family members should be subject to these precautions, as much and no more than any other support arrangement. Provided that is done, self determination must surely include the freedom to use one's individual funding to enable family members to provide support (p 46).*

Another equally restricting practice within some Canadian provinces is that of requiring people who apply for individualised funding to use such funding to purchase support from certified service providers. This systematically imposed limitation is at odds with the basic principles of individualised funding, as it limits consumer choice and diminishes the potential for new options to become available.

In the Roeher Institute study people with disabilities themselves perceived individualised funding arrangements as insecure and therefore as making them vulnerable, rather than more empowered through their involvement in this process. In order to address this insecurity the Roeher Institute suggest removing individualised funding from welfare and creating a new legislative, funding and policy base. One example given was the need for individualised funding to be exempt from being treated as taxable income.

Finally, when individualised funding is discussed the question of whether recipients of individualised funding experience "real" empowerment through this process is often asked. Some people argue that the involvement of personal networks or brokers in actual fact results in people with disabilities continuing to experience a distinct lack of control over their lives. Proponents of individualised funding counter this argument with the view that personal networks and brokers ensure (at the very least) that people with disabilities are involved in decision-making relating to the services they receive. Personal networks and brokers also ensure that services and individuals deliver quality services.

Individualised funding and the implications for services

While individualised funding is generally recognised as having the potential to create significant benefits for people with disabilities, the advantages of this funding model have been questioned by service providers and those in administrative roles. It is clear that individualised funding does represent a challenge to the power and authority of those fulfilling these roles. More significantly, however, individualised funding does present very real implications for the stability of the funding base previously experienced by service providers.

Issues relating to decision-making authority are key considerations for service providers involved in this alternative funding model. The Roeher Institute contend that individualised funding is based on the basic principle of consumer choice. When people with disabilities make choices the question of risk is often raised. The Roeher Institute's own research identified service providers as expressing three main concerns including how to respond when:

- an individual makes a choice that (in the professional's view) constitutes a risk to that individual's safety or well-being
- an individual makes a choice that (in the professional's view) constitutes a risk to other people
- consequences arise as a result of a risk an individual takes knowingly.

Many people with disabilities and disability advocates would affirm the right for people with disabilities to make decisions and to take risks, if they are fully informed of the possible consequences of their actions and able to make informed decisions.

The Roeher Institute study concludes with the following statement.

> *Individualised funding is not a panacea. Yet it provides the means to empower consumers and promote well-being in a way that traditional social welfare services have not. It represents a method of funding that supports choice, community presence, self respect, competence and networks or family and friends (p 98).*

Glendinning, Halliwell, Jacobs, Rummery and Tyrer (2000) provide a historical overview of the individualised funding (direct payment) movement as it developed in the U.K. In the 1970s disabled writers and activists campaigned for the development of housing and support services that would enable disabled people to live independently within the community. Such campaigning was underpinned by the principles of choice and control, particularly choice and control over where to live and choice and control over how support was provided to people with disabilities. Glendinning et al identified three different factors, which led to the eventual introduction of direct payments in the U.K. These factors were: the problems that people with disabilities experienced with the conventional community care services; the Independent Living Movement and the implementation of "third party" direct payment schemes; and the Independent Living Fund.

Glendinning et al commented that by the early 1990s "research evidence mounted on the inflexibility and lack of responsiveness of conventional domiciliary services for disabled people." (p 7). The increasingly specific and narrow range of tasks that home care services were able to provide became problematic for people with physical disabilities who frequently were faced with having to accept support from a wide range of different workers. This made it difficult for people with disabilities to achieve the kind of relationship with their support workers that could lead to greater choice and control over the way support was delivered to them.

> *Direct payments enable disabled adults who need help with a range of daily living activities to buy their own support, for example, by employing their own personal assistant(s) rather than receiving conventional community care services from*

> *their local authority social services department. Direct payment users undergo a standard social services assessment, as they would for community care services, but instead receive regular cash payments which are calculated according to the amount of help they are assessed as needing. They usually opt to recruit one or more personal assistants to provide the support and help they need, at the times and in the manner determined by the disabled employer (Glendinning et al: p 1).*

The second factor which contributed to the introduction of individualised funding was, according to Glendinning et al, the Independent Living Movement. During the 1980s Independent Living Centres were established throughout the U.K. These Centres for Independent Living (CILs) were run by disabled people and offered advice and support to people who wished to move out of institutions. CILs fulfilled a number of functions and were particularly concerned with achieving appropriate housing, transport, an accessible environment, advocacy and training, and counselling and equipment. In addition CILs were also involved in campaigning for personal assistants who would work under the direction of disabled people themselves.

The third factor identified by Gendinning et al as having a significant impact on the implementation of individualised funding in the U.K. context, was derived from the Independent Living Fund (ILF). The ILF was developed and set up in response to an anticipated gap in funding for people with disabilities, after a weekly payment scheme was abolished by the Government in 1988 before the recommendations of a report on community care had been implemented. In order to reduce the negative benefits that this policy change would have on what was originally thought to be a small group of disabled people, the ILF was set up and financed by central government. The financial resources were administered by a charitable trust and means tested "awards" were given to disabled people which were based on an assessment of the help and support that person needed. The awards could only be used to purchase personal or domestic help. The ILF was put in place for a five year period and by the time the scheme closed a total of 22,000 people were receiving payments from the fund. It was originally estimated that the fund would administer approximately 1,500 awards (300 per year) across the five years of the scheme.

The ILF conducted research during this period which determined that a grant from this scheme could enhance and increase disabled people's opportunities for choice and control. ILF users consistently highlighted the positive aspects of choosing their own assistants, and the resulting control and self-respect they derived from this process. Glendinning et al wrote:

> *The unanticipated high demand for ILF grants may partly have revealed and reflected the then current under-funding of services and support for independent living. However, it is also likely that some of that need may previously have remained hidden simply because many disabled people had not applied for or requested what they perceived to be unsatisfactory alternatives. In other words, the ILF may have generated new demands for funds which could secure independence and autonomy (p 9).*

In 1993 the original ILF was wound up and replaced by two new discretionary funds. Firstly, the ILF Extension Fund was implemented to maintain the payments of established clients of the old ILF, and a second fund ILF 93 was developed to “top up” local authority support for people with particularly high needs.

Glendinning et al also provide information about the process by which “indirect” payments became “direct” payments. In the U.K. direct payments were prevented by law until 1996. This situation was due to the 1948 National Assistance Act (which was part of the post-war welfare state framework) which separated cash payments from the provision of services. In summary, this Act prohibited local authorities from paying cash grants directly to individuals. The reluctance to provide direct payments continued for two reasons. First, some local authority associations were concerned that paying cash to individuals would draw them into income maintenance. Second, in 1990 the British Government reminded local authorities that cash payments made to individuals were illegal This policy directive had the effect of ceasing isolated direct payment activities that had been operating within some local authorities.

However, pressure from disabled people and ILCs meant that strategies for bypassing direct payment restrictions were found. For example, some local authorities paid lump sums to local voluntary agencies who in turn administered the money and made payments to people with disabilities. In April 1997 the 1996 Community Care (Direct Payments) Act was implemented. This permissive legislation allows local authorities in England, Wales and Northern Ireland the power to make direct payment to people with disabilities assessed as needing community care services.

In this system potential direct care users are required to have a standard community care assessment to determine their need for services. Direct payments can then be offered instead of the traditional range of services such as home care, day or respite services to people who are both willing to accept such payments and who are able to manage them (alone or with assistance). Glendinning et al noted that direct payments are unable to be used to pay a close family member who may be involved in providing support to their relative with a disability.

The discussion of individualised funding supplied by Glendinning et al also includes the findings of their research in this area. While the study focussed on people with physical disabilities it generated findings relevant to all disability groups attempting to use an individualised funding model. The study involved the perspectives of people with disabilities, personal assistants, health professionals and managers and explores how direct payments can improve the integration of services required by disabled people. Glendinning et al contend that this research confirms, that “direct payments offer disabled people major benefits compared with conventional directly provided domiciliary services. Glendinning et al reported direct payment users as:

- having greater choice and control in terms of the support they received
- being able to design individualised, flexible and responsive support arrangements that were more encompassing than conventional social home care services
- experiencing an enhanced level of independence, quality of life, and emotional and mental well-being.

> *Within the framework set by the initial social services community care assessment, which determined the size of their direct payment, they chose the nature of the support they received, the identity of the person giving the support,*

> *the timing of the support and the way in which elements of the support were provided. Their status as employers lent dignity and respect in the context of receiving help with intimate aspects of personal care. As employers, they also had the power ultimately to terminate the employment of an unsatisfactory personal assistant and to recruit someone else instead (Glendinning et al: p 40).*

While direct payments were seen as highly positive for people with disabilities themselves, Glendinning et al articulated the need to consider the perspectives and interests of personal care assistants and health professionals. For example, personal assistants were often appreciative of the relationships that they were able to develop with their employer, however, they also found that their lack of a formal job description and isolation, was sometimes problematic - leading to high staff turnover. This point raises an issue that is difficult to resolve. Personal assistants suggested that opportunities for formal training and for the acquisition of recognised qualifications was one solution. This approach, however, is at odds with one of the clear advantages of direct payments, whereby disabled people are able to train personal assistants to carry out personal tasks in a way that meets their particular needs and likes. Glendinning et al suggest that one way to resolve this debate regarding the training of personal assistants would be to conduct training that was located within the social model of disability and led by people with disabilities themselves.

Stainton (1996) contends that traditional methods of service delivery are unable effectively to meet the needs of people with an intellectual disability and complex needs. A former service broker himself, he is of the view that direct funding is one way of ensuring that services are tailor-made for the individual Stainton also believes that the long-term effectiveness of direct payments for people with an intellectual disability:

> *will be determined by how well advocates, families and people themselves organise to ensure it is implemented in ways which are about promoting and supporting autonomy rather than simply as a cost saving measure (p 10).*

Stainton provides a useful description of direct funding, a concept which he sees as being applied in various forms. The diverse examples of direct funding, share, in Stainton’s view, two fundamental characteristics: the amount of funding is determined with direct reference to an individual’s needs; and the way the funds are used are determined by the individual Direct payment can involve a cheque or cash being given to the person with a disability to “buy” services of their choosing. In other cases an individual may be allocated funding which is paid directly to a service provider at the discretion of the person with a disability. Another variation of direct funding is the situation where families receive direct funding for their children with disabilities.

Similarly to many researchers and other disability professionals, Stainton contends that direct funding models provide the opportunity for people with disabilities themselves to control the development and delivery of services. If the model is working effectively, people with disabilities have the potential to withdraw funds from services they are dissatisfied with, and to apply pressure for the development of new services better designed to meet their needs. Stainton makes the following statement.

> *In short, money is power – when funds are controlled by the individual, power can potentially follow (p 10).*

Stainton challenges the perception that direct funding is only appropriate for those people who have the skills and ability to manage their own funding. Contrary to this perception, Stainton feels strongly that direct funding is extremely appropriate for people with very complex needs. Direct funding makes it possible to design and implement a unique support package for each individual which has the capacity for flexibility and change. While many people with an intellectual disability are able to identify their support needs and the services that would best meet them, there are a number of areas that can make the implementation of direct payments more difficult. Support in the area of accounting and administration, staff training and recruitment, and technical support, have been found to be useful and effective for those individuals wishing to utilise direct payments.

Clements (1996) provides an alternative view on direct payments/individualised funding. He specifically warns against ignoring some of the real implications of a move toward individualised funding and presents his argument against the backdrop of the 1996 Community Care (Direct Payments) Bill. Clements highlights the fact that research on direct payments has consistently found that this model results in cheaper costs but also a reliance on informal care. Clements contends that these are important findings that deserve greater analysis. The focus on emphasising the positive aspects of direct payments obscures, in Clements' view, some of the challenges of implementing this model of funding.

Clements questions the extent to which direct payments actually achieve genuine political empowerment for people with disabilities. Clements stated:

> *Advocates of direct payments hope that this will be the funding model of the future and they draw a direct line between receiving cash and the empowerment of users (p 8).*

The term empowerment requirements exploration – particularly with reference to what extent people with severe learning difficulty (intellectual disability) actually experience it. Clements provides the example of a situation where a person with a severe intellectual disability receives direct payments, but that decisions regarding the use of such payment are made by that individual's parents. In Clements view this situation may result in an improved service but not in empowerment for the individual concerned. Another concern articulated by Clements is that unless those directly involved with direct payments are able to organise and take control of the process, it has the potential to become just another programme that is not necessary true to the original values/aims of direct payment models.

Clements discusses the finding that providing support through direct payments is cheaper, a finding which he believes is responsible for the change in governmental policy in Britain, from resisting to endorsing direct payments. Savings in support costs are largely due to two factors according to Clements: the continued provision of unpaid care by family and friends; and administrative tasks associated with managing direct payments being managed by people with disabilities themselves or their family or friends. "Direct payments will pass on administrative tasks to the recipient and thus reduce costs." (Clements: p 9). Clements is concerned that the ongoing costs of being an employer will not be incorporated in direct payments. If this provision is not made then savings achieved through direct payments will be accompanied by deteriorating conditions for support workers which is likely, in turn, to directly affect the quality of support delivered to people with disabilities. Clements articulates this view with the following comment:

> *Under the Community Care (Direct Payments) Bill the real locus of power remains unchanged. Central government and the relevant branches decide how to allocate society's resources, while the recipients of direct payments get* ***some*** *say in how they can spend their* ***allocated*** *portion. There are numerous examples in the consultation paper illustrating where the power really lies, for example, local authorities do not even have to offer direct payments – people must be judged by social services to be able to manage direct payments, and money not 'properly' spent will be recovered" (p 9).*

This statement highlights that the power to specify **who** is eligible for direct payments continues to lie with funding agencies. At present, recipients of direct payments are prevented from paying their spouse, partner, or close relative living in the same household to provide a service. This restriction is based on the notion that direct payment legislation should not be the catalyst for an informal support relationship to become a formal one. It is viewed by some people as protecting people with disabilities from being forced to employ their relatives, when they would rather employ an independent person to provide support. The restriction ignores the fact that many people with disabilities want to be able to use direct payments to pay their family and friends to provide the personal support that they require. Clements believes that this restriction on the use of direct payments reinforces the notion of familial duty, which is necessary to ensure the reduced costs of direct payments.

Dowson and Salisbury (2000) also comment on the issue of cost of direct funding. They explain that one argument against individualised funding is that it is too costly while others portray individualised funding as being a more cost effective way of providing services. Further research and evaluation of individualised funding initiatives is required in order to fully understand the cost effectiveness of the model. Dowson and Salisbury assert a need for "care to be taken in the way cost-related objectives are defined and presented in the public and political arenas" (p 64).

Experiences of individualised funding

Aspis (1998) provides an account of how one man with an intellectual disability experienced the direct payment model of funding. Aspis describes the progress in implementing direct payments as being "painfully slow" and contends that care staff who are threatened by their clients using direct payments, are a major barrier for people with an intellectual disability who wish to change to direct payments. Aspis tells the story of Danny. Danny had been unhappy with the services he was using:

> *The staff did not have enough time for you. They had to go and visit other people. You had to be in when the staff could come. Some of them would talk to you funny. I wanted someone who would talk normally (p 21).*

Danny now receives direct payments for 10 hours support per week – support which is delivered according to his own specification.

Interestingly, Aspis (2002) commented on the issue of direct payments for people with an intellectual disability in the United Kingdom in a recent paper. Aspis' paper was written in response to the debate on the Labour Government's White Paper "Valuing People". During the debate it was reported that there had been a 400 per cent increase in the number of people with an intellectual disability using direct payments. (While the article does not specify, one would assume that Aspis means that this increase has occurred since the introduction of the 1996 Community Care (Direct Payments) Act.) Aspis asserts that this figure does not accurately reflect the current situation for people with an intellectual disability and direct payments because those receiving direct payments commonly receive "just a few hours per week".

A practical example of a direct payments scheme run by Swindon People First is detailed by Harbridge (1999). Harbridge highlights the fact that Direct Payment legislation in the United Kingdom has effectively reduced the opportunities for people with an intellectual disability to access direct payments. This is because the legislation requires the applicant to be able to give informed consent. In some cases this has resulted in local authorities being reluctant to introduce direct funding schemes. Harbridge also asserts that barriers to the implementation of direct payment schemes have included:

- a lack of knowledge and experience within funding organisations about direct payments
- a lack of confidence in the applicant's support structure
- uncertainty about union reaction to perceived threats to employment.

The Swindon People First have employed Direct Payments workers. The role of these workers is:

- to provide information about direct payments
- to help people with an intellectual disability develop support networks; help with direct payment applications
- to assist with employing personal assistants
- ensuring that the person with a disability remains at the centre of assessment processes
- to support those receiving direct payments in all areas.

Those involved with this particular project make the valid point that "Direct Payments are not necessarily about being unhappy with services but about moving on."

Maglajlic, Brandon and Given (2000) report on research conducted in the London Borough of Tower Hamlets. People with an intellectual disability, mental health service users, and people with physical disabilities were the three client groups included in this study. Data for the study were generated through interviews with people with disabilities themselves, interviews with informal carers, and interviews with staff employed in disability support services within the London Borough of Tower Hamlet. This study was designed to explore the following issues:

- how to provide information on direct payments
- what kind of support would payments be used for?
- access to direct payments

- support systems – for whom and what kind?
- handling payments
- monitoring and evaluation.

Maglajlic et al presented findings which were specific to each participant group. With regard to people with an intellectual disability, their informal carers, and staff involved in intellectual disability services, Maglajlic et al reported a significant lack of knowledge about direct payments. People with an intellectual disability were found to be disadvantaged by direct payment information that was not presented in a manner accessible to them. Maglajlic et al also reported that staff, who are central in providing information to their clients with an intellectual disability, need to be better informed about direct payment options. Family carers are another group who need to be made aware of direct payments. Maglajlic et al noted that this information is particularly important around the transition to adult intellectual disability services for young adults with an intellectual disability.

This study generated valuable information relating to people with intellectual disabilities' own views of direct payments and how they could be used in their own lives. One participant in this study made the following comment.

> *People make conservative choices. Users would love to go to pubs; have holidays; shop; own a dog; chat to someone; play snooker; buy their own clothes. But some people around here don't, because they don't know how much money they get, they don't know how to count money. I can. I know about the money you need to put away, how much you spend. My key worker explained it to me (p 102).*

According to Maglajlic et al, in order to encourage greater use of this funding model people with an intellectual disability, informal carers, and staff need to receive:

- greater details
- more literature
- clarification of material received
- contact with other people using direct payments
- contact with a direct payments office (p102).

Maglajlic et al conclude with a statement which points clearly to some of the critical issues of implementation for people with disabilities who wish to access direct payments.

> *Nevertheless, these groups are cautiously enthusiastic about what direct payments might offer them. They see the possibilities for much more control and flexibility and, in some cases, an escape from the local authority swamp However, they are anxious about the various practicalities. How would they manage the money? How and by whom would it be monitored? Where could they get examples of it working well? (p 111).*

Simon-Rusinowitz, Mahoney, Shoop, Desmond, Squillace and Stowers (2001) provide some answers to the above questions. This study was one component of the implementation of a funding model called the Cash and Counselling Demonstration and Evaluation (CCDE) which “offers a cash allowance and information services to persons with disabilities, enabling them to purchase the services, assistive devices, or home modifications that best meet their needs.” (p 87). The CCDE model is currently being evaluated through a demonstration project involving three American states (Arkansas, Florida and New Jersey). The current paper presents results of a telephone survey which aimed to assess interest in direct payment option (CCDE) for Florida adults with developmental disabilities. Simon-Rusinowitz et al specifically were interested in exploring: how many consumers (or surrogate decision-makers) would choose a cash option; who would choose cash versus agency based personal assistance services; and what were attractive/unattractive about cash options.

The survey data represented the views of 378 adults with developmental disabilities. One hundred adults with disabilities themselves responded to the telephone survey and 278 (74%) of adults chose to have surrogates answer for them. This does raise a methodological issue relating to what extent the study actually reflects the views of adults with disabilities themselves.

Results of the study are summarised below.

- Forty percent of those surveyed indicated an interest in direct payments.

- Fifty-nine percent of consumers and 57 percent of surrogates had not received more than a high school education, leading Simon-Rusinowitz et al to conclude (similarly to Maglajlic et al) that informational materials need to be straightforward.

- More Hispanic (67%) and African American (52%) consumers were interested in a direct payment options than European (36%). This same pattern was observed in surrogate responses.

- The consumers with the highest level of disability were most interested in direct payment options (61%) leading to Simons-Rusinowitz et al to reiterate the need to find ways to include all people with disabilities in direct payment efforts.

- Reflecting the methodological difficulties associated with using surrogates to represent consumers, the data showed surrogate decision-makers expressing high levels of interest in direct payments when stating their own views, and less interest when asked to answer the same question from the perspective of the disabled person they were representing.

- Surrogate interest in direct payment options decreased as consumer and surrogate age increased, suggesting that parents of aging adult with disabilities may be exhausted from care giving and unwilling or unable to give their time or energy to this new model.

- Consumers most dissatisfied with their current services were more likely to be interested in direct payments.

- Consumers who wanted to have more control over the selection and scheduling of their own services were most interested in direct payments.

- Surrogates' interest in direct payment was generated by: the belief that direct payments would result in greater flexibility and independence; their willingness to take on employer related tasks; and a perception that direct payments would make their life easier.

Summary

This review has shown the extent to which individualised funding is being promoted as an alternative model of funding for people with disabilities. It is clear that individualised funding originated within the physical disability movement as a way of ensuring that people with physical disabilities received attendant care in a manner that was determined by them and best met their needs. In most cases, individualised funding has been used to enable people with physical disabilities to purchase attendant care from services and individuals of their own choice.

Recently, the individualised funding movement has gathered momentum. Many countries now provide some kind of individualised funding to people with disabilities (including those with an intellectual disability). The benefits of individualised funding are linked to the concept of self-determination. In particular, the ability of people with disabilities to control their own finances is seen by some proponents of individualised funding as being central to self-determination. Other benefits of self-determination have been identified. Such benefits include:

- greater access to services and the ability to create support configurations that best meet individual needs
- increased eligibility for services (due to the fact that people identify their own support needs)
- more responsive services
- greater personal empowerment.

However, the intended aims and benefits of individualised funding are not always realised. Limitations of individualised funding have been reported as including:

- an over reliance on the demand-supply argument that does not reflect the fact that it is difficult to facilitate the development of new services (and it unlikely that individualised funding alone will make this happen)

- disparity in the way that individualised funds are allocated (that is two people with the same needs may receive very different allocations depending on where they live, how articulate they are, or how well a personal advocate or broker is able to present their needs)

- a greater level of personal responsibility for managing budgets and staff (that not all people with disabilities may wish to assume)

- limitations on the types of services that some recipients of individualised funding are able to purchase

- the perceived insecurity of individualised funding arrangements.

If individualised funding is to be implemented widely a number of other issues need to be considered. In particular, the issue of planning support or funding brokerage continues to be under debate. Further to this point, the areas of accountability, evaluation and monitoring are viewed in multiple ways according to one's perspective on individualised funding. Finally, payment of individualised funds to family members who provide care remains one of the most contentious issues in this area. The desire to respect individual requests to be able to pay family members who provide necessary support must be balanced against possible exploitation of people with disabilities by their families.

CHAPTER SIX

CONCLUSIONS

> *At the individual level, people with intellectual disability must be given every opportunity to exercise decision-making in areas that concern their lives, even when it is easier for others to do so. They must be given help to develop confidence and other skills that enable them to put their views forward and select from the opportunities available. They must be exposed to a variety of opportunities so that their decisions can result from the selection of one of several opportunities for selection. Choice, the act of deciding upon and selecting one option of several needs to be both respected and applauded by those other people who are meaningful in the life of the person with (an) intellectual disability (Brown 1999: p 304).*

Adults with an intellectual disability experience the same challenges as other people with low incomes and/or who are reliant on state provided income support. Having a low income limits people's ability to participate in community life, to be involved in recreational activities of one's choice, and to pursue goals and choices. For adults with an intellectual disability, many of whom struggle with these aspects of life already, low income levels exacerbate, and perpetuate exclusion from these areas.

This review has highlighted a number of issues that must be considered if adults with an intellectual disability are to have the ability to extricate themselves from the cycle of poverty that many find themselves in.

1. Adults with an intellectual disability are at risk for poverty. It is important to challenge the assumption that poverty is an expected outcome for people with an intellectual disability and to understand the factors that contribute to poverty in their lives.

2. If adults with an intellectual disability have only a small amount of disposable income available after paying for support services, their ability to participate in their community is seriously limited.

3. There is a further issue of whether adults with an intellectual disability even know what their income is or have any say in how their disposable income is spent. There is also a suggestion that while families frequently are responsible for managing the finances of disabled family members, they may not always be the most appropriate people to do so. There is a clear need for New Zealand research in this area.

4. Further to the above point, adults with an intellectual disability must not only be informed about their income and how it is being managed for them, but they must also have opportunities for learning how to manage their own money. There is a large body of literature on structured teaching and adaptive strategies which can be applied to supporting adults with an intellectual disability to manage their own money.

5. Under-representation in employment by adults with an intellectual disability is related to their frequent experience of poverty. Supported employment models have been identified as having a positive impact on the hourly rate of pay for employees with an intellectual disability. Continuing attention must be paid to increasing employment opportunities for adults with an intellectual disability, with people with an intellectual disability themselves involved in the development of employment initiatives.

6. The link between low income level and employment opportunities for adults with an intellectual disability has been consistently highlighted throughout this review. The interface between income generated through (usually) part-time employment and the benefit eligibility for New Zealand adults is particularly problematic.

7. In order to reduce disadvantage, adults with an intellectual disability must be well informed about benefit entitlements, and be kept up-to-date with changes to benefit related policy. This will ensure that adults receive the income support that they are entitled to, and that they can make informed decisions about employment related activities. Some people, for example may be too frightened to uptake employment when the financial risks are minimal or conversely, begin employment which is financially disadvantageous to them.

8. Particular attention must be paid to addressing the above issues for women with an intellectual disability who are as likely to be affected by gender to the same extent as disability in the areas of poverty, income and work.

9. Individualised funding is increasingly being seen as an alternative model for funding the purchase of services for adults with an intellectual disability. This review has highlighted a number of unresolved issues which need consideration if individualised funding were to be introduced for adults with an intellectual disability in this country. In particular, the issues of brokerage; payment to family carers; cost-effectiveness; and the views of people with an intellectual disability themselves, need to be comprehensively addressed through research.

References

Aspis S. 1998. How Danny gets to be the boss. *Community Living,* July/August 21.

Aspis S. 1999. Will this Bill be a disincentive to work? *Community Living,* April/May 6-7.

Apsis S. 2002. A lost opportunity? Parliament's first debate on Valuing People. *Community Living*: 15(3): 6-7.

Beresford P. 1996. Poverty and disabled people: challenging dominant debates and policies. *Disability and Society* 11(4): 553-67.

Berry T. 1999. *Minimum Wage: Making it work – The implications of the national minimum wage for people with a learning disability.* London: Mencap

Bewley C. 1996. Their money in our hands. *Community Living,* July 11.

Bleasdale M. 1995. Supported living, disability services and the politics of funding. *Interaction* 5: 25-9.

Bray A. 2003. Work for adults with an intellectual disability. Literature Review prepared for the National Health Committee: In press.

Bright A. 2001. Direct payments: can the USA learn some lessons from us? *Community Living* 15(2): 17-19.

Brown F, Evans I, Weed K, Owen V. 1987. Delineating functional competencies: a component model. *Journal of the Association for the Severely Handicapped* 12(2): 117-24.

Brown I. 1999. Embracing quality of life in times of spending restraint. *Journal of Intellectual and Developmental Disability* 24(4): 299-308.

Butterworth J, Gilmore D. 2000. Are we there yet? Trends in employment opportunities and supports. *TASH Newsletter,* June/July 5-8.

Clements T. 1996. Direct payments: are they all good news? *Community Living,* October 8-10.

Corden A. 1997. *Supported employment, people and money.* York, U.K: Social Policy Research Unit.

Cox J. 1989. The stigma of poverty: Being on welfare means living below the poverty line. *Entourage* 4(3): 11.

Disability Counts. 1998. Wellington: Statistics New Zealand .

Dowson S, Salisbury B. 2000. *Foundations for freedom: International perspectives on self-determination and individualised funding.* Baltimore: TASH.

Drew B. 1998. “Camping out is no way to live”: Young people who are homeless and have an intellectual disability. *Interaction* 11(2): 5-11.

Fulton S, Sabornie E. 1994. Evidence of employment inequality among females with disabilities. *The Journal of Special Education* 28(2): 149-65.

Glendinning C, Halliwell S, Jacobs S, Rummery K, Tyrer J. 2000. *Buying independence: Using direct payments to integrate health and social services*. Bristol, U.K: The Policy Press.

Harbridge E. 1999. Moving on with direct payments. *Community Living*, October/November 16-17.

Holman A. 2000. The minimum wage – a mixed blessing? *Community Living* 14(1): 11.

Holman A. 1999. A service user breaks the mould. *Community Living*, October/November 10-11.

Holman A. 1997. Our age for change. *Community Living*, April, 4-8.

Hyde M. 2000. From welfare to work? Social policy for disabled people of working age in the United Kingdom in the 1990s. *Disability and Society* 15(2): 327-41.

Kainova T. (with Cerna M.). 2000. We like working. In R Traustadottir and K Johnson. *Women with intellectual disabilities: Finding a place in the world.* London: Jessica Kingsley Publishers.

Kitchin R, Shirlow P, Shuttleworth I. 1998. On the margins: disabled people’s experience of employment in Donegal, West Ireland [1]. *Disability and Society* 13(5): 785-806.

Maglajlic R, Brandon D, Given D. 2000. Making direct payments a choice: a report on the research findings. *Disability and Society:* 15(1): 99-113.

Mank D, Cioffi A, Yovanoff P. 1999. Impact of co-worker involvement with supported employees on wage and integration outcomes. *Mental Retardation* 37(5): 383-94.

Mank D, Cioffi A, Yovanoff P. 1998. Employment outcomes for people with severe disabilities: Opportunities for improvement. *Mental Retardation* 36(3): 205-16.

Neufeldt A, Sandys J, Fuchs D, Logan M. 1999. Supported and self-directed support initiatives in Canada: An overview of issues. *International Journal of Practical Approaches to Disability* 23(3): 24-36.

New Hampshire Self Determination Project. 1995. An Affirmation of Community: A revolution of vision and goals – Creating a community to support all people including those with disabilities. *Tash Newsletter* 21(7): 19-23.

Noble M, Platt L, Smith G, Daly M. 1997. The spread of disability living allowance. *Disability and Society* 12(5): 741-51.

O'Brien D. 2000. The ticket-to-work and supported employment: How will it work? *TASH Newsletter,* June/July 9-10.

Oliver M, Barnes C. 1998. *Disabled people and social policy: from exclusion to inclusion*. Harlow: Longman.

Pathways to Inclusion: Nga ara whakauru ki te iwi whanui – Improving vocational services for people with disabilities. 2001. Wellington: Department of Labour.

Reid P, Bray A. 1997. Paid work and intellectual disability. *Journal of Intellectual and Developmental Disability* 22(2): 87-96.

Revell W, Wehman P, Kregel J, West M, Rayfield R. 1994. Supported employment for persons with severe disabilities: positive trends in wages, models and funding. *Education and Training in Mental Retardation and Developmental Disabilities,* December: 256-64.

Robinson E, Rathbone G. 1999. Impact of race, poverty, and ethnicity on services for persons with mental disabilities: Call for cultural competence. *Mental Retardation* 37(4): 333-8.

Rusch F, Heal L, Cimera R. 1997. Predicting the earnings of supported employees with mental retardation: A longitudinal study. *American Journal on Mental Retardation* 101(6): 630-44.

Sandra (with Jan Walmsley). 2000. "Two pounds is not enough." In D Atkinson, M McCarthy, J Walmsley, M Cooper, S Rolph, S Aspis, P Barette, M Coventry and G Ferris, *Good times, Bad times: Women with learning difficulties telling their stories.* Worcestershire, U.K: BILD Publications.

Schneider J, Simons K, Everatt G. 2001. Impact of the national minimum wage on disabled people. *Disability and Society* 16(5): 723-47.

Schloss P, Wolf C, Schloss C. 1987. Financial implications of half- and full-time employment for persons with disabilities. *Exceptional Children* 54(3): 272-6.

Simons K. 1998. *Home, work and inclusion: the social and policy implications of supported living and employment for people with learning disabilities*. London: Rowntree Foundation.

Simon-Rusinowitz I, Mahoney K, Shoop D, Desmond S, Squillace M, Sowers J. 2001. Consumer and surrogate preferences for a cash option versus traditional services: Florida adults with developmental disabilities. *Mental Retardation* 39(2): 87-103.

Stainton T. 1996. A concept tailor-made for people with complex needs. *Community Living,* April 10-11.

Steele D. 1997. Beware the 16-hour trap *Community Living,* January 14-16.

Steele D. 1996. Is the honeymoon over? *Community Living,* October 16-18.

Taylor J. 1996. Supported employment for individuals with intellectual disability. *New Zealand Journal of Disability Studies* 3: 30-50.

The G. Roeher Institute. 1988. *Income Insecurity: The disability income system in Canada.* Downsview, Ontario: The G. Roeher Institute.

The Roeher Institute. 1993. *Direct dollars: A study of individualised funding in Canada.* North York, Ontario: The Roeher Institute.

Thompson L, Powers G, Houchard B. 1992. The wage effects of supported employment. *Journal of the Association for persons with Severe Handicaps* 17(2): 87-94.

Traustadottir R. 1990. *Women with disabilities : Issues, resources, connections.* Syracuse, NY: Syracuse University Centre on Human Policy.

Zilber D, Burnett D, Castro D. 1993. Productivity based wages and career structure in a small business model. *Interaction* 6(4): 30-2.