Work 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 1: Introduction

When young people become adults they are expected to get jobs and be responsible for themselves. People with disabilities want to work in paid jobs too, but they may need support. As well as the pay, people with disabilities like to be proud of going to work.

In the past, other people thought that adults with an intellectual disability could not work, so they were usually given a benefit to live on. Then sheltered workshops were set up to provide useful work with other people with disabilities, but people were only paid a small amount to work there. Also, working in a sheltered workshop hardly ever led on to a real job.

As more was found out about how to help adults with an intellectual disability to learn, some of them began to work in real, paid jobs in ordinary workplaces. A new way of helping people to work developed called "supported employment".

Supported employment means:

- finding a job and putting a person in it
- training the person on-the-job and supporting them until they can do it by themselves
- being paid
- accepting everyone who wants to work, no matter what their disabilities are
- the job must be a real job, with other people who do not have disabilities
- giving support if people want to change jobs.

There are supported employment services now in many countries, including New Zealand. There are also lots of sheltered workshops and day centres for adults with an intellectual disability.

There are lots of reasons why it may be hard for adults with an intellectual disability to have paid jobs like other people. Some countries, including New Zealand, have laws that say it is wrong to discriminate against people with disabilities. This can help employers to be fair when looking for new workers.

Some countries say employers have to employ some workers with disabilities. Sometimes employers get extra money to employ workers with disabilities.

Some of the time it is hard for lots of people to find jobs, or the jobs might require skills and qualifications that people do not have.

The government does need to decide how it can best organise funding and help so that adults with an intellectual disability can work when they want to. At present, most countries seem a bit muddled in all the different ideas and ways of helping people to work. It is also hard to get a job if you are on a benefit because you can lose your benefit and not earn enough money to live and pay for extra expenses and support.

Adults with an intellectual disability now live in the community and they are asking to **work** in real jobs in the community too.

Chapter 2: What do adults with an intellectual disability say about work?

In all of the studies that ask people what they think, many adults with an intellectual disability say they would like to work in real jobs in the community. However, often their parents or support workers do not think they are able to have a job.

The reasons adults with an intellectual disability want to work are:

- for the money
- because they are bored
- to learn new things
- to have a career
- to be more independent.

Most adults with an intellectual disability need support to find the right job and they also need help if problems arise later on.

Adults with an intellectual disability like the social contact and support they get in sheltered workshops, but still usually say they would like to work in ordinary jobs.

Adults who have got jobs with the help of supported employment seem to have better lives – more independence, more things to do – than adults in sheltered workshops. They are also usually more satisfied with their work.

Sometimes adults with an intellectual disability have not been totally satisfied with their jobs. Their concerns are:

- wanting more hours of work
- low pay
- unkindness from other workers
- need to have a different job or career
- needing more on-going support and advice
- worrying about losing the benefit
- the pressure and stress in some jobs.

Adults with an intellectual disability sometimes do not think they can learn new skills, and may tend to blame themselves if they are not socially included at work. It can sometimes be hard trying to "fit in" at work and make new friends.

Some people think it would be better if adults with an intellectual disability could have the money to buy their own employment support service. There is also a need to involve adults with an intellectual disability in planning and evaluating their support services.

One New Zealand study found that adults with an intellectual disability did like working in sheltered workshops that were like small businesses. They enjoyed the variety of work and liked the people they worked with.

Chapter 3: How many adults with an intellectual disability do work?

Studies have been done to see how many young people with an intellectual disability get jobs after they leave school. Most of these studies have been done in the US where high schools have special programmes to help young people with disabilities learn adult skills. These programmes are called "transition services".

These studies give different results, but on the whole, they found that many students with an intellectual disability did **not** get jobs after leaving school. They were more likely to get jobs if they had had part-time work while they were in high school. Women were **less** likely to get jobs than men.

Unemployment among adults with an intellectual disability is much higher than it is for other people. Even after the US developed better high school and transition services, people with an intellectual disability were still not doing a lot better in terms of employment.

Unemployment is a problem for adults with mild disabilities as well as those with severe disabilities.

After the development of supported employment services in the US, more adults with an intellectual disability were employed than before. However, women were still less likely to get jobs, and the jobs they did get were not as well paid or as permanent.

A recent New Zealand study showed how a good transition programme and supported employment programme helped young people with an intellectual disability get jobs. This shows that if the right support and training is provided more adults with an intellectual disability could have paid jobs.

Chapter 4: Are families a help or a problem?

Parents sometimes find it hard when their children with an intellectual disability grow up. They still worry about them and sometimes find it hard to let their adult sons and daughters become more independent.

When it comes to the question of work, families can be a big help in lots of ways:

- practical help, like giving a ride to work
- encouragement to work hard
- making sure their sons and daughters are not treated unfairly at work
- involving their sons and daughters in family activities.

It may be hard for adults with an intellectual disability to find a job and do well at work without the support of their families.

Some studies have found that parents wanted their sons and daughters to have real jobs in the community, others would rather that they stayed in workshops and centres. Parents may not know about supported employment services and how they can help adults with an intellectual disability find jobs and do well in them.

Parents of young people today are likely to be more keen on their sons and daughters with an intellectual disability going out to work like everyone else.

Parents may need support and information to help them understand how to be good parents of an adult. Most support for parents, unfortunately, is given when their children are young.

Staff and parents may also need to learn how to get on better together. It is best for adults with an intellectual disability if everyone works well together to support them.

Chapter 5: Will employers give jobs to adults with an intellectual disability?

When employers have been asked about employing someone with an intellectual disability, most have been quite positive. If they have already employed someone with an intellectual disability, they are usually even more positive.

Employers appreciate the help they get from supported employment services. This help also means they find the workers are better at their job too.

Even when employers find that workers with an intellectual disability are slower, they still say they are reliable, hard-working, and loyal workers.

Studies of employers have usually found that big businesses are more positive about employing adults with an intellectual disability than small businesses. Employers are often willing to "give a person a chance", if they want a job and are prepared to work hard and do their best. Employers feel good themselves when an adult with an intellectual disability does well in a job.

Staff who work in supported employment services need to focus on giving employers information on how adults with an intellectual disability can be good workers. They also need to tell employers how staff can help to make sure the job works out well for both the worker and the employer.

When staff in supported employment help a worker on the job, they need to make sure they fit in and do not make the worker look different to other workers.

Employers often provide training and support for their employees, and this should also be available to employees with an intellectual disability. A good place to work – where people support each other and get on well together – is likely to be a good place for adults with an intellectual disability to work too.

Chapter 6: Supported Employment

In the 1970s and 1980s, some University researchers in the US found that adults with severe disabilities could learn work tasks if they were taught very carefully. These studies led to adults with an intellectual disability working in small groups in real workplaces, and being paid for their work.

After this, individual adults with an intellectual disability were supported and taught to work in ordinary jobs. This way of helping people to succeed in jobs became known as "supported employment". This is one example of how research can lead to better lives for adults with an intellectual disability.

With more adults with an intellectual disability learning to work in the community, schools and other services need to change too, so that everyone is working towards the goal of real work.

Supported employment services are now available in many countries, including New Zealand. However, they vary in terms of how well they succeed in helping adults with an intellectual disability find jobs and keep them. Another problem is that there are not enough supported employment services to meet the needs of all the adults with an intellectual disability who want to work in the community.

Even though supported employment was developed specially to help adults with severe disabilities get work, not enough of this group is getting into supported employment programmes. Most of this group are still in sheltered workshops and day centres.

Providing long term support at work

Supported employment services provide long term support for adults with an intellectual disability at work – as much as the person needs to do the job well and get on with other workers. Sometimes supported workers may not get paid until they have learned to do the job, but this does not happen very often.

The staff person who provides support on-the-job is usually called a "job coach". This person provides training in the job, solves problems with the worker, and helps the worker make friends. The "job coach" can also help the person look for better jobs, as they get more skilled.

Sometimes adults with an intellectual disability can lose their jobs because they have problems in doing the job well or problems getting on with other workers. Job coaches can help the worker to improve in these areas and keep their jobs.

One of the problems for supported employment services is getting enough funding for them to support people in jobs on a long term basis.

The role of the job coach

Being a job coach is not an easy job – it takes a lot of skills and knowledge about work and about supporting and teaching adults with an intellectual disability.

When a job coach works with an adult with an intellectual disability, most of the time is spent at the beginning:

- finding the right job to suit the person
- helping the employer and other workers to understand and be able to support the adult with an intellectual disability
- teaching that person how to do the job
- helping to sort out any initial problems or other things to learn, like how to get to work independently.

Studies have shown that job coaches do not always have the qualifications and skills they really need. One of the problems is that they are not usually paid enough for what they are expected to do. Another problem is the lack of training courses on supported employment. Staff want practical training from experts in supported employment.

Employers are generally pleased with the way that job coaches help adults with an intellectual disability to do their jobs well.

Some adults with an intellectual disability also have physical disabilities. They may need someone to help them with their personal needs, like going to the toilet. It can sometimes be difficult to get the funding to pay for this sort of help at work.

Job coaches do not want workers with an intellectual disability to rely on their help too much. They want workers to gradually become more independent. Job coaches have to gradually provide less help, so the worker asks other workers for help if it is needed.

In supported employment, getting help and support from other workers is called using "natural supports" in the workplace.

Using natural supports in the workplace

Studies have found that other workers can be very good at supporting adults with an intellectual disability to be good workers in ordinary jobs in the community. Sometimes job coaches can help other workers to learn how they can support workers with an intellectual disability.

Sometimes managers and other workers do not want to help train a new worker who has an intellectual disability. Some workers do not know how to teach and be supportive.

Job coaches can help the worker with an intellectual disability to make friends with other people at work. How they do this will be different for each worker.

Studies have generally found that when other workers have been trained to support adults with an intellectual disability at work, these adults do better in their job, earn more, and

have more friends at work. For the best results, other workers need to be involved in supporting the adult with an intellectual disability at work, from the very beginning.

In terms of support at work, too much **or** too little can be a problem. It needs to be the right amount at the right time for each individual worker with an intellectual disability.

Does supported employment cost too much?

People have sometimes said that supported employment cannot be worth the money because it works with one person at a time and provides support for as long as the person needs it.

Studies that look at the costs and the benefits of any service are called "cost-benefit studies". Cost-benefit studies of supported employment services have been done since they first started in the US in the 1980s.

All of these studies have shown that supported employment services save the government money after two to three years. Why is this?

- If adults with an intellectual disability are not in jobs with supported employment, they will likely be in sheltered workshops and day centres which the government also pays for.

- When adults with an intellectual disability earn wages, they also pay taxes like other workers. This tax goes to the government.

- Some adults who work in community jobs can get off the benefit. This saves the government money because it pays for benefits.

- Adults in supported employment have more money to spend than they did before they had a job.

- As adults with an intellectual disability get better at their jobs and more independent, paid job coaches usually do not need to spend much time helping them.

Also, the benefits eventually outweigh the costs even for workers with a severe intellectual disability.

A New Zealand study has also shown that supported employment services are well worth their cost – they benefit both the government **and** adults with an intellectual disability.

Chapter 7: Ways of supporting adults with an intellectual disability at work

Supported employment is a service for everyone with an intellectual disability, including people with severe disabilities. However, people with severe disabilities have not usually done as well at work as other people with an intellectual disability. They often work

fewer hours and earn less money. They need more support from job coaches. Many of the jobs they have can be boring and hard work.

Studies have shown that there are ways to make it more likely for adults with severe disabilities to succeed in their jobs. One way is to train other workers to give them the right support.

People are often positive about adults with severe disabilities having jobs in the community. It might take them longer to learn, but they can learn if they are taught very carefully, step by step.

Even people who have difficult behaviour can learn to cope with a job in the community. They need well trained staff to help them overcome their problems.

Adults with autism and those with Asperger's syndrome (a form of autism) can also work with the help of supported employment. Job coaches need to match the person and the job carefully, and help the employer and other workers understand about autism.

Adults with physical disabilities can also be supported to work, using supported employment. The job coach may need to design a job specially for the person.

Sometimes special efforts are needed to find out what sort of job people would like. If they cannot talk, staff need to take time to find out what they like or do not like. Even people who are deaf and blind have been included in work with supported employment services.

Improving work skills

If workers are too slow or do not do their job quickly enough, they may not be able to keep their jobs.

Studies have shown that there are ways to help adults with an intellectual disability to learn to improve their work skills. Sometimes it is enough to change the way the job is done, to make it easier and quicker to do.

Another important factor is fitness. If adults with an intellectual disability are unfit and unhealthy, this will slow them down at work.

Adults with an intellectual disability can learn to work more quickly by checking how well they are doing themselves. This means they are also more independent and do not need someone else supervising them all the time. They can learn to set their own work goals and check on their own work. They can also have lists to check off that they have done all the tasks.

Improving social behaviour

Sometimes adults with an intellectual disability can do their jobs well but they have problems in getting on well with other workers. For example, they may be too shy, or they may talk too much and annoy other people.

There are two types of social skills that are important at work:

- learning to follow instructions and do what you are asked to do; asking for help
- learning to get on well with other workers.

Everyone **learns** these behaviours as they grow up. If adults with an intellectual disability have not learned them very well, they can be **taught** them.

Studies have shown that adults with an intellectual disability can learn to show better social behaviours at work. Job coaches need to be able to help the person to learn these skills as well as how to do the actual job.

Being in a real job also gives adults with an intellectual disability lots of chances to learn social skills by listening and watching what other workers do.

Social skills are very important in jobs where workers deal with members of the public, like shops or restaurants.

Improving social skills also makes adults with an intellectual disability feel better about themselves.

Job coaches may need to ask other workers to tell them which social behaviours are most important in that particular workplace. They may also need to help other workers to change **their** behaviour towards the worker with the intellectual disability.

Social integration at work

One of the reasons that adults with an intellectual disability want to work in ordinary jobs is so they can be part of the community and make more friends.

However, simply being in a job does not always mean the worker with the disability is included in social activities at work. Also what is expected in one workplace can be very different in other workplace. Therefore learning exactly how to interact with other workers is not always easy for adults with an intellectual disability.

Some social behaviours are accepted with one person but not with another person. Social interactions are very complicated and it is not always easy to learn when to do what. Taking part in conversations with other workers is sometimes difficult too, but adults with an intellectual disability can be helped to learn how best to talk with other workers. Sometimes another worker can help more than the job coach, in helping the person to learn how to interact with other workers.

Studies have shown that adults with an intellectual disability can be lonely at work. Even if they do make friends at work, they may not see these friends outside of work.

Chapter 8: Other types of day services

There are still not enough supported employment services for all adults with an intellectual disability. Sometimes small groups of adults with an intellectual disability work together in a community workplace, or go out to do jobs like gardening or cleaning. But most adults with an intellectual disability work in sheltered workshops or go to day services.

There are other types of services in some places. A "work co-operative" involves people with disabilities working together with non-disabled people in a type of small business. They do real work and get paid for it. One of the worries people have about being paid is that they might lose the benefit they get from the government.

Some work cooperatives are owned by people with disabilities themselves. This gives them more say in how it is run, and gives them dignity and pride in their work.

Another work option is "self-employment" or working in your own business. An adult with an intellectual disability who is good at a particular job or good at making something useful, can be supported to set up their own business. They will need other people to help them do this. Working for yourself may suit some adults with an intellectual disability better than working with other people. One of the hardest things may be getting the money to get started.

People in the community can be a good source of help and advice when it comes to setting up employment services for adults with an intellectual disability.

Some adults with an intellectual disability may not find suitable jobs, or may only work part-time. They may need some sort of support during the day when they are not at work. What sorts of support or services are best? What sorts of activities would people like to do? Studies have not answered these questions.

It is important that adults with an intellectual disability have the support they need and have interesting things to do when they are not at work. They may like more education, or to learn how to become more independent in their communities.

When adults with an intellectual disability retire from work, they will need support also to be active and enjoy their retirement.

Chapter 9: Changing services for adults with an intellectual disability

The New Zealand government has said that disability services need to change so that they:

- help people with disabilities get jobs
- help people with disabilities take part in community activities.

Many of the disability services at present do not help people into jobs. Neither do they all help people become involved in their communities.

How hard is it for services and organisations for adults with an intellectual disability to change the way they provide support?

Studies have been done in other countries to find out about changing services. In particular, they have looked at changing from sheltered workshops to supported employment services.

These studies showed that it is not easy to make these changes. It was easier to set up new supported employment services than to change old services. Even when extra money was provided, change was difficult.

Even though many more adults with an intellectual disability now have jobs through supported employment, many adults are still in segregated services.

Some studies show that disability services **can** change to supported employment. For example, one organisation changed over five years to having 80 percent of its clients in real jobs. Before that, no one had a real job. These studies give lots of good ideas about how to change and what works best. It is important to get support for change from people with an intellectual disability, staff, and parents. Many people are frightened of change and need information and support.

These studies also show that it takes a lot of commitment, time, and hard work – from the government down – to change services to supported employment.

Some people have said that as long as segregated services are still funded, they will not change. However, there is still the issue of how to support adults who do not have a job or only work part-time.

There are some barriers to change:

- people not sharing the same ideas and goals about work for adults with an intellectual disability
- families being opposed to change
- lack of enough funding (money)
- lack of skilled staff, and opposition by some staff
- need for strong leadership
- trying to operate old services and new services at the same time.

The government has an important part in encouraging and helping disability services to change and develop. Without clear government direction and requirements, most services are unlikely to change. Also, benefit systems often get in the way of people working, because they can end up with less money.

Supported employment services also need to do better in terms of giving adults with an intellectual disability more job choices.

Over time, while studies show that there are more supported employment services, there are also more segregated services. They have also shown that, in the US, adults with an intellectual disability are earning **less** than they were eight years ago.

It is important that research is done to show us just what is happening for adults with an intellectual disability.

Supported employment is like supported living. It is about helping each adult with an intellectual disability get a paid job they like in the community. Supported living is about helping each adult **live** in the community. They are both new ways of thinking that are different to old ways. They involve different types of services too. People need help to understand these different ideas and how they can mean different ways of supporting adults with an intellectual disability in their own communities.

Chapter 10: What we found out?

This book has told us about what studies of adults with an intellectual disability and work have found out.

These studies have shown that:

- supported employment services provide the best way we know to help adults with an intellectual disability work in paid jobs in the community
- most adults with an intellectual disability do want to work
- there are not enough supported employment services for everyone that would like to get a job
- supported employment services save money for the government in the long run
- it is not easy to change segregated services into supported employment services.

We need research in New Zealand to give us a clearer picture of what is happening for adults with an intellectual disability who want to work in community jobs. We also need research so we can see whether any changes have good results for adults with an intellectual disability.

CHAPTER 1

INTRODUCTION

> *The world of work is changing, and everywhere the growing preoccupation of working age men and women, including people with disabilities, is how to get and keep a job. People with disabilities have a right to work and must have access to the same range of work opportunities in the open labour market as are available to non-disabled workers. Productive work provides a person with livelihood, status and self-esteem, and is the most effective way to achieve economic and social integration (Joint Statement of the ILO, UNESCO, UNICEF and WHO 1999, cited in Lunt 1997: p 155).*

Work is such an accepted part of the way of life for adults that those who do not work may be seen as unwilling or unable to work. These perceptions may be tempered by considerations of the current state of a country's labour market and level of unemployment, but there can be no doubt that the positive value placed on working contributes to self-esteem and identity as a citizen. Work means more than income (Jolly 2000).

Most adults with an intellectual disability have traditionally been perceived as unable to work, and therefore it has been seen as the responsibility of charity and/or the state to provide income and, sometimes, supervised daily activities. During the 1950s and 60s "special" work settings for adults with an intellectual disability proliferated, and sheltered workshops became the most common "work" in which adults with an intellectual disability were involved.

Many sheltered workshops do provide a "work-like" environment and real work tasks (using contracted work), but the major concerns about sheltered employment which began to be expressed in the 1970s were:

- the congregation of people with disabilities into segregated settings
- the generally low expectations of the "workers"
- the minimal (if any) pay received for the work done
- the frequent lack of qualifications and expertise in the staff
- the fact that "sheltered work" hardly ever led to "real work" in open employment, even for the most competent workers.

Challenges to the assumption that most adults with an intellectual disability (particularly moderate or severe disabilities) could **not** work in the open labour market, first arose from behaviourally based research in the 1960s and 1970s which demonstrated the power of structured teaching strategies (Parmenter 1993). People with a severe intellectual disability were shown to be capable of learning quite complex tasks. An early pioneer in applying behavioural technology to teaching work tasks was Marc Gold in the US, whose catch phrase "Try Another Way" became the motto of much of the early research and developments in the area of work for adults with an intellectual disability (Gold 1980 cited in Henderson 1990). With evidence accumulating as to the ability of people with a severe intellectual disability to learn, if they were taught appropriately, assumptions about unemployability were no longer tenable. When these teaching technologies were then

applied successfully in the context of open employment settings, the rationale for sheltered work was severely challenged (Rusch 1990).

There was also another source of the growing unrest with segregated vocational and day services for adults with an intellectual disability. The influence of principles such as normalisation and integration, along with a growing human rights movement of people with disabilities, also fuelled the impetus for changes to traditional, segregated day activity and vocational services for adults with an intellectual disability.

The result of all these intersecting influences was a new type of service in the 1980s for adults with disabilities who wanted to work – Supported Employment. As Rusch (1990) explains:

> *The concept of supported employment reflected a reversal in our thinking about mental retardation in two ways. First, supported employment held that the issue was not whether people with severe disabilities can perform real work, but what support systems were needed to achieve that goal… Second, the concept proposed that the unsuccessful "place and pray" orientation, commonplace in education and rehabilitation, should be replaced by the more pragmatic approach of finding a job for the person with disabilities and then providing the training necessary for successful integration (p 6).*

What is "supported employment"?

Proponents of supported employment have offered varying definitions, and variations are seen in the legislation and funding regulations in different countries. There is, however, general consensus on the key characteristics of supported employment among the leaders in the field. Bennie (1996), a key leader in initial developments in New Zealand, sets out the following "consistent set of core values or principles that express what supported employment is, underpins how it is practised, and makes it instantly recognisable from traditional approaches to job placement for people with disabilities (p 2)". These six core principles are:

- ***Placement first.*** This approach is a complete reversal to the traditional "getting ready" approach of traditional rehabilitation and vocational services. While careful career planning, based on the individual's preferences, and careful job matching, are important parts of the process, the commitment to placing people in jobs **with** the training and support on-site, is an essential component of supported employment.

- ***Ongoing Support.*** Support is provided on the job, for as long as it is necessary, to enable the worker to succeed and stay in work. At the same time, the aim is to reduce this type of external support and assist the workplace and co-workers to provide more "natural" and less intrusive support.

- ***Financial remuneration.*** Supported employment is focussed on achieving paid work for people with disabilities – "real pay for real jobs". Any unpaid "work experience" should be strictly time-limited and have a specific goal. One of the continuing barriers to appropriate pay and hours of work are the disincentives

posed by government income support systems (benefits) for disabled people. (These issues are discussed in the review on "Income".)

- ***Universal eligibility.*** Supported employment was originally developed to enable people with the most severe intellectual disabilities to work in "real" jobs. This principle means that level or type of disability should not be used to deny people access to supported employment services.

- ***Integrated settings.*** Supported employment is only about work in ordinary work settings in the open labour market. It cannot be used to describe work in "sheltered workshops". As Bennie (1996) explains, "Supported Employment **is** open employment (p 4)".

- ***Career development and choices.*** People should be supported to advance in their jobs and to change jobs, if they wish, to further their careers. While this principle poses serious challenges in reality, the centrality of choice is important.

The growth of supported employment – in all countries – has required strong advocacy and leadership (Steele 1994, for example, describes leadership in the European Community). In New Zealand, this leadership has come largely from ASENZ (the Association for Supported Employment in New Zealand) which was formed in 1994 by a group of supported employment providers (Mannion 1996). ASENZ has also provided a strong educational role, with its annual conferences, publications, quality standards, and the recent development of a staff qualification in supported employment. ASENZ has promoted best practice in supported employment based on research evidence **and** New Zealand's own unique cultural context (ASENZ 1999).

There is a lack of published data on the extent of supported employment in New Zealand, particularly in view of the contradictory and varying definitions sometimes used by funders (Bennie 1996). However, Mannion (1996) reported that funding for vocational services from the Community Funding Agency in 1997 amounted to $3.5 million for supported employment and $10.8 million to sheltered workshops. Mannion notes that 51 of the 65 contracted providers for supported employment provided **both** sheltered workshops and supported employment.

Another "snapshot" survey of 10 supported employment programmes was undertaken by ASENZ in 1997 (Bennie 1997). From these data, a picture of a "typical" supported employment programme was described as:

- serving 65 consumers with 21 of these in paid employment
- employing about 4 staff with an average staff: consumer ratio of 1:19
- in operation for about four years
- having 55 people on its waiting list
- receiving $10,697 per month in direct government funding
- serving primarily people with an intellectual and/or a psychiatric disability, aged 20 to 50 years
- located in a city or larger provincial centre (Bennie 1997: p 42).

Bennie also highlighted the enormous inconsistencies at that time in the funding provided, with prices per placement outcome ranging from $510 to $4,372 (p 40).

Similar leadership exists in New Zealand for the large array of vocational services through VASS (The New Zealand Federation of Vocational and Support Services) which recently published best practice guidelines (VASS 2001).

There have been calls for greater unity in the interests of their clients, among vocational service providers in New Zealand, in order to lobby for a coherent, long-term strategy to promote and support employment for people with disabilities (Winter 1996).

This brief description of New Zealand developments is provided as a "backdrop" against which to consider the review of research on work for adults with an intellectual disability. Unfortunately the vast majority of this research has been undertaken in other countries, particularly the US. However, there is considerable evidence which can provide very useful lessons and implications for New Zealand.

Before considering the research, it is important to be aware of the broader policy, legislative, and societal influences which significantly affect the employment of adults with disabilities.

The policy context for employment of people with disabilities

Whether people with disabilities are employed or not depends on far more than their own ability to work and research showing how they can be supported to work. Parmenter (1993) outlined how the vocational opportunities available to people with an intellectual disability must be studied in the context of international trends and national and local contexts (p 360). In a review of employment policies for disabled people in 18 countries, Thornton and Lunt (1997) analyse how different countries respond to this issue in varying ways, even though all share the policy ideals of equality and social integration of people with disabilities.

Countries approach disability and employment in differing ways, in their policy and legislation (Thornton and Lunt 1997). Anti-discrimination legislation is common in most countries, and is present in New Zealand in the Bill of Rights Act 1990, the Human Rights Act 1993, and the Human Rights Amendment Act 2001. Brereton (1997) was optimistic about the role of such legislation in the employment of people with disabilities in New Zealand. Even with such legislation, however, the largest number of complaints of discrimination, mostly in employment, still come from disabled people in New Zealand (Human Rights Commission 2001), and Canada (Crawford 1992). Roulstone (2000) argues that "anti-discrimination law is likely to benefit those who are already socially advantaged, it is also highly unlikely to change employer behaviour (p 440)". However, there is some positive evidence from the US as to the effect of anti-discrimination legislation. Miller (1999) reports that in the first two years after the passage of the Americans with Disabilities Act in 1992, 800,000 more people with severe disabilities entered the workforce (p 162). At the same time, people with an intellectual disability were unlikely to file charges under the Act with the Equal Employment Opportunity Commission (EEOC), but Miller describes some successfully litigated cases on behalf of workers with an intellectual disability who were unfairly fired.

In the second type of approach identified by Thornton and Lunt, disability policies are divided and developed within specific government departments. They found that some countries relied on legal requirements, such as quota systems, particularly in European countries, whereas countries with human rights provisions did not use these types of measures. A variety of types of financial incentives are sometimes provided to employers, to "reward" them for employing people with disabilities (Lunt and Thornton 1994: p 230). Overall, Thornton and Lunt (1997) found a "piecemeal approach to meeting employment needs" and a "marked proliferation of measures", with continuing "fragmentation of disability policy" (p 298). These findings are supported by researchers in other countries, for example in Canada (Crawford 1992).

Thornton and Lunt also found an increasing emphasis on "the right to work", largely brought about by strong advocacy from people with disabilities themselves. These changing policy directions are also evident in "The New Zealand Disability Strategy" (2001) and "Pathways to Inclusion" (2001).

Other policy trends evident were attempts to address the unequal opportunities in the workplace and in access to work (p 299). There has been a marked shift from paternalistic intervention to policies that emphasise independence and responsibility – rhetoric which can also mask state concerns with controlling welfare expenditure. A number of policy researchers have provided critiques of "new deal" policies for disabled people in the UK (Glendinning 1991; Jolly 2000; Roulstone 2000) and in New Zealand (Sullivan and Munford 1998). Thornton and Lunt (1997) note a striking trend to include disabled people within general labour market strategies, with a growing view which sees "exclusion from work" as a "matter for economic policy, rather than for welfare policy" (p 299).

Fortunately, there also appears to be increased recognition in policies of the individual differences in the employment needs of people with disabilities, with a wide range of disabled people, including those with severe disabilities, now seeking employment. Positive trends in employment policies identified by Thornton and Lunt included:

- disability is clearly on the employment policy agenda
- increasing moves to prevent job loss in the first place
- providing increasing employment opportunities for people with severe disabilities (eg, supported employment)
- the growth of small, localised, specialist services
- a growing divergence between policies aimed at keeping people in work and those aimed at getting people into work for the first time
- growing alternatives to publicly provided services
- an increased range of legislative, voluntary, and financial measures and services
- increasing use of international evidence and approaches to inform policy development (eg, in Europe, an increasing move to a civil rights approach) (p 311-2).

On the more negative side, Thornton and Lunt found that:

> *there is no single coherent disability employment policy in any of our study countries. Typically, the objectives of policy are unclear and we have noted the consequent internal contradictions and tensions (p 312).*

Policy development also occurs within the context of a changing labour market. Lunt (2002) provides a valuable critical analysis of changes in the UK and their effects and relates these to the New Zealand situation.

He notes the similarity between the UK and New Zealand in the move from a governmental commitment to full employment to "a new social contract around the notion of employability (p 7)". Along with this trend go emphases on transferability of skills, mobility and short-term contracts.

Labour market changes are also the result of global changes (Chapman 1998; Lunt 2002) resulting in, for example:

- a decline in manufacturing
- a growth in the service sector
- a shrinking public sector
- the streamlining of large firms
- outsourcing and a growth of smaller employers and of self-employment
- a shift in the location of employment eg, home based work has increased (Lunt 2002: p 8).

These types of labour market changes can have significant effects on the employment of disabled people, often with advantages to some groups but disadvantages to others (Jolly 2000; Parmenter 1993). For adults with an intellectual disability, many of the changes pose difficulties, for example, working a series of temporary jobs. Part-time work is particularly found in the service sector, (91% of part-time workers work in the service sector), an area in which many adults with an intellectual disability look for paid work.

Lunt also notes the critical role played in employment outcomes by other policies and provisions, such as an inflexible social security benefits system, transport, housing, support services, and education and training (p 20-1). Adults with an intellectual disability face disadvantages and barriers in all of these areas of life which impinge on their access to and success in employment.

What might a coherent disability employment policy look like? Lunt and Thornton (1994) suggest the following characteristics:

- it offers employment and opportunities
- it offers integration within mainstream employment (that is, it does not stigmatise)
- it is built on a sound philosophical and theoretical base of what constitutes disability and is built on rights rather than charity (again it does not stigmatise)
- it is not contradictory (either internally or in relation to other policies)
- it requires disabled people themselves to participate in the development of policy
- it pays attention to costs and considers the opportunity cost of pursuing certain types of policy (p 236).

The increasing presence of adults with an intellectual disability in ordinary work settings in the community provides the same sort of challenges as integration in other areas of civil society. As Parmenter (1993) concluded:

> *… just as the presence of children with mental retardation in the mainstream of education challenges us to re-examine the role and goals of education, the emerging phenomenon of community-based employment for people with mental retardation is a challenge for policy development in the labor market sphere (p 366).*

Summary

There is a growing international acceptance that people with disabilities have a right to be included in paid work in their communities. However, adults with an intellectual disability have typically been perceived to be unable to work, and have received income through state benefits.

Sheltered workshops were developed to provide a type of special work setting, in which people with disabilities were congregated together and the normal work demands and rewards were varied. Concerns grew in the 1970s about the segregation and poor outcomes of sheltered work provisions. Developments in teaching strategies and an increasing emphasis on integration and civil rights for people with an intellectual disability led to a new type of vocational service called "Supported Employment". This service model placed people with an intellectual disability into paid jobs, trained them on-the-job, and provided on-going support to the extent necessary for job success. There was an emphasis on serving people with a severe intellectual disability.

The growth in supported employment has occurred in all Western countries, including New Zealand. Much of its growth has depended on strong leadership from within the disability sector.

Social and employment policies and legislation are also influential factors on the inclusion of adults with an intellectual disability – and people with disabilities, in general – into the world of work. Most countries use a variety of approaches to employment policy, with resulting fragmented and sometimes contradictory approaches. There is, however, evidence of a growing trend which emphasises the rights of all people to work and growing recognition that adults with an intellectual disability can be supported to work. Changes in the labour market also affect adults with an intellectual disability, often to their disadvantage, with a growing need for more skills and flexibility in the work environment.

But do adults with an intellectual disability want to work? What experiences do they have at work? The first section of this research review will examine the evidence from adults with an intellectual disability themselves.

CHAPTER TWO

THE VIEWS OF ADULTS WITH AN INTELLECTUAL DISABILITY ABOUT WORK

There is an increasing body of research evidence describing the work aspirations and experiences of adults with an intellectual disability. This research generally supports the claim that people want "real jobs" and value their opportunity to work.

Job aspirations

McConkey and Mezza (2001) surveyed 275 adults with an intellectual disability who attended three day centres in Belfast, Northern Ireland. More than one-third of this group aspired to having a job, but their key workers thought only one in five would be able to hold down a job, and only four people had ever been in any paid employment. The highest proportion of those aspiring to real work was among those who had had work experience placements. These findings confirm the direction of the Government's new strategy for vocational services ("Pathways to Inclusion") with its emphasis on employment. McConkey and Mezza point out that because employment boosts people's self-esteem and confidence, the benefits of work may extend to alleviating the high rates of depression found amongst adults with an intellectual disability. Thus the long term cost effectiveness of employment initiatives are likely to be greater than merely income and service cost outcomes.

Similar work aspirations were found among sheltered workshop clients in Hong Kong (Li 1998). Although all of these 23 adults were motivated to have employment, their self-determination was severely limited by parents' views and lack of appropriate professional support. These adults with an intellectual disability all valued work highly and had individual reasons for this, as illustrated in the following direct quotations:

> *I like to work because I want to earn money (p 212).*
>
> *I don't like the workshop and residential environments because I get very bored here. If I have the opportunity to work outside, I shall earn more money and I can move out of the residential setting (p 212).*
>
> *I prefer to have work outside because I want to learn more and earn more money. But Mom doesn't want me to leave the workshop (p 212).*
>
> *The staff need to look for jobs for me because I don't know how to look for jobs. I hope some employers will hire me… I prefer to work outside because I want to earn more money. I also want to have more friends and know more about the community (p 213).*

The professionals interviewed in this study considered that "the attitude of parents was the major obstacle in assisting sheltered workshop workers with an intellectual disability to move on to open employment" (p 214).

A New Zealand study confirms the general finding that adults with an intellectual disability are motivated to work for the same reasons as the rest of the adult population, "real pay for real jobs" (Reid and Bray 1998). Fourteen adults with an intellectual disability and their nominated support persons were interviewed about their experiences in paid work. The hours of work and type of jobs varied, with nine people working less than half-time. Most workers had very clear views on why they worked:

> … *no money, no nothing. Nothing to do (p 232).*

Half of the group said that they worked for the money, with two having managed to get off all benefits and others aspiring to reach this independence. Other reasons cited for working were:

- relieves boredom
- learning new things
- improving their career prospects
- keeping fit.

Many people believed they got the job because of their own strong work ethic. One woman believed others could do more for themselves to get jobs:

> *They should be getting up and doing, getting out, getting staff to help them find jobs out in the community instead of sitting doing (sic) around and doing nothing. They could be doing more for their selves, get staff to find their jobs, look in papers and find what jobs are here, around in this area, and get motivated (p 233).*

These workers also had career aspirations – to work more hours, or move on to a better or different job – but there was no evidence that they had any support to pursue these aspirations. They also showed a realistic appreciation of their own difficulties, and identified work they would not attempt or jobs they had left because 'they were too hard' (p 234).

Although the social opportunities of work are often cited as highly important, five of these adults worked with no one else even present in the work setting eg, cleaning. While others did have social interactions with fellow workers, only one person experienced this outside of work hours.

Two men had been successful in staying in fulltime work and both had now bought their own homes. Another woman in part-time work had also managed to purchase her own home. Having to get themselves to work had also motivated people to learn how to get around their community, thus increasing their general independence and control over their lives.

This study also found that support services played a critical role in enabling each person to get their job, and were also valuable "at any later stage if work problems or issues arose" (p 238). Short term job finding and placement services are not enough for some adults with an intellectual disability. Long-term **availability** of appropriate support appears to be important. This is confirmed by Reid and Bray (1997) who note that:

> *No one found jobs by themselves. The most successful jobs were found through a paid person who understood the abilities or potential of the worker, knew employment legislation and regulations, could match person to position, and who had networks and entrepreneurial skills that would lead to employment chances (p 94).*

Curry and Cupples (2001) outline participatory action research with users of three day services in the UK, two of which were for adults with an intellectual disability. Data were gathered through small group interviews, with a group of trained service users acting as researchers, with support. The research found a high interest in work as an alternative to daycare, with clear understanding of the value of work and the status it brings. Many people did not know of the variety of jobs that even people with severe disabilities could do. People valued their day centre for the support and social contact it provided. They expressed a preference to work in teams with people they knew and liked, and believed people should be paid to work. Some were willing to work for no pay because of the high value they placed on working. These adults were also very realistic about the areas in which they would need support to be able to work.

The types of services typically provided for adults with an intellectual disability include: day centres, sheltered workshops, and supported employment. What are their experiences with these different services?

Comparisons between supported employment and sheltered work

Research has compared the views of adults with an intellectual disability who were in supported employment with those in sheltered workshops.

The range of positive outcomes from employment in the community is supported in a study by Sinnott-Oswald, Gliner, and Spencer (1991). A quality-of-life survey was administered to three matched groups of adults: adults with an intellectual disability in supported community employment; adults with an intellectual disability in sheltered workshops; and adults without disabilities, matched on age and gender. Supported employment was found to be positively related to quality of life, defined as: environmental control, community involvement, and perception of personal change; the number of leisure activities; use of leisure time; self-esteem; involvement in activities; mobility; job skill perceptions; and perceptions regarding changes in income.

Griffin, Rosenberg, Cheyney and Greenberg (1996) studied the overall job satisfaction and self-esteem of two groups of 100 adults with a mild intellectual disability. Higher levels of job satisfaction were found in the adults in supported employment who also lived semi-independently. Self-esteem was related to job satisfaction for both groups of adults with an intellectual disability.

A study by Jiranek and Kirby (1990) looked at a range of relevant comparisons across groups of young adults and work settings and examined their job satisfaction and psychological well-being. Three groups of young adults with an intellectual disability (in competitive employment, sheltered workshops, or unemployed) were compared with two groups of young, non-disabled adults who were in competitive employment or were unemployed. The authors summarise their results as follows:

- For both those with an intellectual disability and the non-disabled, competitive employment was a more positive alternative than unemployment in terms of psychological well-being.

- Those with an intellectual disability generally had lower psychological well-being in comparison to the non-disabled regardless of whether they were employed or unemployed.

- For those with an intellectual disability, competitive employment was a more positive alternative to sheltered employment in terms of job satisfaction but not in terms of psychological well-being.

- For those with an intellectual disability, self-esteem in competitive and sheltered employment were similar and higher than in unemployment (p 133).

Another way to obtain a comparison is to follow up individuals who have experienced both types of service. Murphy, Rogan, Handley, Kincaid, and Royce-Davis (2002) interviewed 16 adults with visual and multiple disabilities (including nine with an intellectual disability), eight years after they had been involved in an agency's conversion from a sheltered workshop to a community employment programme. The interviews were semi-structured and in-depth, and some people were interviewed twice. Staff members who had worked closely with the 16 disabled adults were also interviewed.

In terms of employment outcomes, 15 had found at least one competitive job, only seven were still working. All adults had earned more than the minimum wage but all were working part-time.

People expressed initial enthusiasm about leaving the sheltered workshop but also had some initial fears about employment in the community, with some anxiety about the changes persisting for a few people.

Even though many had experienced job loss, most were determined to find another job. Five people rejected community work, with three returning to a sheltered workshop or day programme, and two deciding not to work at all. Some people had long waiting periods between jobs, and this was a source of frustration, as one woman said:

> *I was promised and promised and it [a job] did not come. I was hanging around until I went to adult day care… I know it is not the best thing for me, but it is better than nothing. I am not going to hang around the house (p 34).*

Thirteen of the adults interviewed were positive about the service changes, but some people had specific concerns about their work eg, more money and hours, more predictability, more stimulating work.

Murphy et al conclude that the overall reports from those involved described many positive benefits from working. The disappointing finding is that "despite preferring and being capable of competitive work," some of them ended up in segregated settings "because of systemic obstacles as much as the rigors of community employment itself" (p 36).

Experiences of supported or open employment

Although most studies have identified positive experiences and benefits of real work, some adults with an intellectual disability have described negative experiences and dissatisfaction. Di Terlizzi (1997) held five focus groups with 35 adults with an intellectual disability to talk about their work placement or employment. The majority liked their job as it brought purpose and increased social opportunities into their lives. However, the following concerns were also raised:

- some workers wanted to increase the hours worked; most only worked 3-7 hours per week
- dissatisfaction with low wages; almost all were paid a lower rate than other workers in the same job
- negative interactions with other employees
- lack of clarity about future job or career prospects
- few opportunities to explore and discuss different types of work
- staff assistance was crucial to obtain job placement, but did not continue into assisting the person to improve their performance at work
- the fear of loss of benefits deterred people from leaving day services.

Another area which has been studied is the experiences of people with disabilities in job interviews. Duckett (2000) analyses "real life" job interview experiences of people with disabilities and non-disabled people but does not include the sample characteristics. It is not clear, therefore, how many of the participants had an intellectual disability.

People described their job interviews as a "battle" and interviewers as "interrogators", leading to defensiveness on the part of the person being interviewed. Because of the intense competitiveness of the job market, people felt intense pressure and anxiety in job interviews, and felt the need to "hide" their disability if they could. Some participants reported the use of questions which they perceived as "trick" questions or irrelevant, and they found such questions intrusive. Disabled participants also noted the "nervousness" of some interviewers, in response to their disability, and sometimes their increasing self-consciousness.

One interviewee noted his positive experiences, which he attributed to the fact that the employer already had other disabled employees.

Participants felt they had to "prove themselves" in their job interviews. Overall, their experience was "of a social setting that could be considerably hostile (p 1032)".

It was rare for interviewees to receive any feedback on their job interview, and sometimes they never even received notification that they had been unsuccessful. This lack of feedback was of great concern to the disabled interviewees, and made it very difficult to identify discrimination by the potential employer.

Test (1994) explored research on consumer satisfaction with supported employment in terms of the acceptability or social validity of the goals, procedures and outcomes of supported employment. In addition to people with disabilities, this review of 30 studies included other "indirect consumers" or "stakeholders", such as employers. The findings

reported here relate only to the "direct consumers", ie, supported employees. The studies reviewed supported the following broad conclusions that supported employees:

- were satisfied with the broad social goals of supported employment
- were satisfied with specific aspects of their job
- preferred supported over sheltered employment
- were satisfied with the specific procedures in the supported employment process
- were pleased with the more indirect effects of supported employment on their quality of life.

The majority of participants in these studies had a mild to moderate intellectual disability, and most studies were limited to "one-time" measures of satisfaction. Test calls for research which uses a wider array of measures and includes people with severe disabilities.

The perspectives of adults with an intellectual disability may not always concur with their employers or support staff. For example, Chadsey-Rusch, Linneman and Rylance (1997) studied the varying beliefs about social integration outcomes and interventions in employment settings. Three stakeholder groups were studied: adults with an intellectual disability; job coaches; and employers. Two groups of adults with a mild to moderate intellectual disability were studied: 23 young adults at high school, and 24 young adults who had left school. All of these young people worked in integrated employment sites. The job coaches also fell into two groups ie, those who worked with each of the two groups of young people with disabilities. All of the groups were involved with the same "transition" services. The young adults were all interviewed, while the 29 job coaches and 20 employers completed mailed questionnaires.

The study found that **none** of the stakeholder groups viewed social integration outcomes the same way. For example, adults with an intellectual disability believed that barriers to social integration were more significant than did the job coaches. Chadsey-Rusch et al ask the critical question, "If stakeholders do not agree then which group should establish the outcome agenda? (p 10)". They suggest, that if consensus cannot be reached, then adults with an intellectual disability should make the decision on what are desired social integration outcomes at work.

Employers and job coaches were both skeptical about interventions to increase social integration. Adults with an intellectual disability believed that the biggest barrier to social integration was that people with an intellectual disability have trouble learning new skills, but employers did not believe this was a barrier. This finding supports the need to focus on the issues of attitudes and self-esteem among young adults with an intellectual disability, who may internalise and take responsibility for their lack of social acceptance by others. Chadsey-Rusch et al conclude that "contrasting belief systems could interfere with the achievement of social integration" (p 11) for workers with an intellectual disability. This study "provides a detailed look at what is meant by 'social integration' from the perspective of multiple groups who may have a different stake in the outcome (p 2)".

Test, Bond, Hinson, Keul, and Solow (1993) interviewed 34 people to explore their satisfaction with supported employment services and with their job. The majority of the participants liked their jobs and appreciated the services of their job coach. They

expressed a clear preference for working in the community and enjoyed their friends at work. Of those 28 people who had previously worked in a sheltered workshop, 93 percent preferred their present job to the workshop.

The research on job satisfaction draws on the finding in the general employment literature that job satisfaction is related to psychological health. Petrovski and Gleeson (1997) examined this relationship in a group of 31 adults with an intellectual disability in competitive employment, through self-report questionnaires and one or more interviews. The measures of psychological health in this study were: self-esteem, stigmatisation, loneliness, and aspirations. The study found a high level of job satisfaction. However, the workers also described negative experiences at work, and 40 percent said they would like to work somewhere different, with boredom often cited as a reason.

Workers who felt the highest job satisfaction also felt the least stigmatised and were less lonely. Many workers described how they consciously tried to "fit in", with 47 percent feeling "different" from others at work and being uncomfortable with this. While most said they had friends at work, this friendship did not extend to out-of-work contact.

The study found no relationship between job satisfaction and the measures of self-esteem and aspirations. The only significant difference found between men and women was a higher degree of loneliness at work perceived by the women. Petrovski and Gleeson conclude that "a 'job satisfaction' measure is not enough if we are to have a clearer understanding of the nature of job satisfaction for workers with an intellectual disability (p 208)".

Sartawi, Abu-Hilal, and Qaryouti (1999) provide evidence from a Middle Eastern cultural context. They explored the views of 161 disabled people (of whom 24 had an intellectual disability) in the United Arab Emirates and Jordan about their work training programme and work environment. It is not clear whether the work they were involved in was in sheltered or open employment settings. The retrospective evaluation of their training did not provide any consistent findings. However, the variables of "psychological support" and "suitability of the training environment" were positively related to perceptions of the work environment.

The views of adults with an intellectual disability are increasingly being heard and sought in supported employment service planning and evaluation. Brooke, Wehman, Inge, and Parent (1995) describe a "customer-driven" model in which adults with disabilities can exert choice and control. They noted two surveys of people with disabilities (in 1986 and 1994) which showed that the percentage who want a job had increased from 66 percent to 79 percent.

In contrast to a paternalistic approach of "professionals know best", "we, the professionals are in charge", Brooke et al call for a "customer driven" approach. In this approach, the customer (adult with a disability) requires services that would best fit the **customer's** need, rather than what is convenient for the service. They note that such an approach works best in communities that use voucher systems to purchase services. It is also clear that this "market model" approach also relies on the existence of choice and the availability of a number of options. In an ideal world, such a model would shift power from the provider to the customer, and service providers would enter into partnerships with the customers of their service, who would be equal partners in all areas of supported

employment policies and practice. Brooke et al provide detailed lists of the practical implications of their proposed model.

Adults with an intellectual disability are also being acknowledged as critical contributors to the evaluation of employment services. Young and Ludwig (1996) note that while services have become more "client-driven" in their services to **individuals,** adults with an intellectual disability have seldom had any **collective** involvement in service planning and evaluation. The study reported used participatory action methodology, and explored how the clients of a service felt about their work in a sheltered setting and/or in the community.

A group of adults with an intellectual disability who were also clients of the service took an active role in planning and undertaking the research. The resulting information was used in the agency's strategic planning and to inform service change.

Experiences of sheltered work

There appear to be few published studies of the views of adults with an intellectual disability in sheltered workshops, even though this is still the most common placement.

Robinson and Fitzgerald (2001) studied the job satisfaction of 153 people with various disabilities working in three sheltered workshops in New Zealand run by the same organisation. Most of these workers had a mild or moderate degree of disability, with 52 having an intellectual disability. The research explored the influence of previous education (mainstream, special class, and special school) and previous employment experience (mainstream, sheltered employment, and no other job). None of these factors were found to be significant in affecting reported job satisfaction. Robinson and Fitzgerald found that all participants expressed similar high levels of job satisfaction. This study challenges the assumptions that all people in sheltered workshops experience low job satisfaction, **and** that all sheltered workshops are the same. Robinson suggests that a sheltered workshop can offer conditions of employment similar to those of a small, private sector business. The three work sites in this research offered a range of work, including assembly, packaging, print-finishing, and manufacturing. All employees – disabled (72%) and non-disabled (28%) - were employed under the same collective contract with variations in the hourly rate of pay, and 98 percent worked fulltime.

Focus group discussions with the workers suggest possible reasons for the (unexpected) high levels of job satisfaction in these three sheltered workshops. All participants agreed that the most valued aspect of work was interaction with co-workers. Variety of work and opportunities to try different tasks were also appreciated. Some people did say that the work could be boring or that there was not always enough to do. Pay was important but most were satisfied with their wages (most only $50 per week, on top of their benefits). Understanding supervisors and bosses were also rated as very important. People who had previously worked in competitive jobs had sometimes found the pressure and high expectations stressful.

Robinson and Fitzgerald (2001) concluded that:

… an oversimplified dichotomy such as, mainstream employment is always good and better than sheltered employment, is not necessarily helpful or true… to many of the participants it (sheltered employment) was a real job… … the level of expressed job satisfaction is the result of a complex interaction between person, job and workplace, not just the characteristics of the workplace (p 76).

Summary

People with an intellectual disability have similar work aspirations and reasons for working as others of the same age, but these aspirations may not be supported by others on whom they rely for support. Adults with an intellectual disability who do have paid work in the community report many benefits from this, extending to other areas of their lives as well.

Although they enjoy working, some adults are dissatisfied with their low wages, hours of work, and lack of career development, but these concerns may often not be heard or addressed.

For most adults with an intellectual disability, support services are essential to help the person find a suitable job, and to support them in the job, when needed.

Social integration at work may occur for some adults with an intellectual disability, but some experience lack of social acceptance and loneliness. They may also perceive this as due to their own lack of skills, even though they usually try hard to "fit in". Interactions with co-workers are valued by adults with an intellectual disability, and can be a positive part of sheltered work. However, most comparison studies have found that they prefer open employment to working in sheltered workshops.

The views and preferences of adults with an intellectual disability about work and careers should be actively sought and provide the central focus for supporting them to work. They also have an important role to play in service planning and service evaluation.

CHAPTER THREE

LONGITUDINAL AND FOLLOW-UP STUDIES OF SCHOOL LEAVERS

Since the 1980s, a number of studies have sought to identify the adult outcomes of secondary education and transition programmes for young adults with an intellectual disability. The majority of these studies refer to the USA, where high school and transition programmes have been a major focus of legislative and educational reform over the last 15-20 years. For example, the US Individuals with Disabilities Education Act (IDEA) requires the provision of transition services for students with disabilities, preferably at age 14, but no later than 16 years. The definition of transition services is:

> *Transition services means a coordinated set of activities for a student, designed within an outcome oriented process, which promotes movement from school to post school activities, including postsecondary education, vocational training, integrated employment, including supported employment, continuing adult education, adult services, independent living or community participation. The coordinated set of activities shall be based upon the individual student's needs taking into account the student's preference and interest and shall include instruction, community experiences, development employment, and other post school adult living objectives, and when appropriate acquisition of daily living skills and functional vocational evaluation.*

Paid employment has been the primary outcome measure in follow-up studies, but many have also included adult education, independence in daily living, and mobility. This review will focus primarily on employment outcomes.

There are a number of methodological problems in these follow-up studies, particularly when they are intended to provide an evaluation of high school programmes. Haring and Lovett (1990) provide a summary of common problems in this research:

- restricted geographical location of participants
- lack of clarity in the definition of those included
- changes in the definitions of disability categorisations over time
- the limited nature of data collection
- inadequate description of the content of high school or transition programmes
- variations in the definition of "employment"
- lack of experimental control, limiting group comparisons
- samples may not represent the population of school leavers
- it is often not possible to track all school leavers
- most research examines **recent** school leavers, but other research suggests improvement in employment outcomes over time (p 53-4).

Employment outcomes for any population group are also affected by a multitude of personal, contextual, and historical variables. Lunt (2002), for example, provides a thorough examination of the complex effects of changing labour markets and social policies on the employment of disabled people. Therefore, research evidence on

employment outcomes for adults with an intellectual disability must be considered in the light of the historical and cultural context of that particular time period (Wehman 1992).

Studies of adults with an intellectual disability published during the 1980s found varying rates of employment. Hasazi, Gordon and Roe (1985), in a study of 301 high school leavers from 1979-1983, found over 50 percent were employed. The majority (84%) had found jobs through their "self-family-friends networks" and males were 30 percent more likely than females to be employed. The most significant predictor of employment was involvement in paid part-time or summer jobs during high school. Work experience, as part of the high school programme was **not** a predictor of later employment.

Another earlier study which only included adults with moderate, severe, and profound intellectual disabilities found a much lower rate of employment among school leavers. Wehman, Kregel, and Seyfarth (1985) found less than 12 percent of their sample of 117 school leavers in Virginia held competitive jobs in non-sheltered work environments. Wehman et al point out that this high level of unemployment still occurred at a time of job expansion and relatively low unemployment in the general population.

Low rates of employment were also found in a New Zealand study of two samples of school leavers with a mild intellectual disability. Wilton, Tuck, Yates, Irwin and Coffey (1988), in two Auckland samples, found 40 percent and 25 percent of these two groups were in open employment. The rates of unemployment (24% and 18%) were almost three times the rate for all school leavers during the study period. ("Unemployment" was distinguished from being in special work schemes or being in sheltered employment). Wilton et al report that "almost all of the subjects interviewed who were in sheltered employment, expressed reservations and concerns about their employment status and wished to secure open employment (p 241)."

Another New Zealand study of young people with a moderate intellectual disability who were due to leave school and some who had already left, also showed very low expectations for future work (Westwood and Mitchell 1988). The expectations of families, teachers, and many of the young adults, were limited to a future in sheltered workshops, or to "don't know" (p 248-9). Both of these New Zealand studies were published at the same time as supported employment programmes were growing rapidly in other countries.

A Scottish longitudinal study (Richardson, Koller and Katz 1988) also found low employment rates among young adults with an intellectual disability, compared to a comparison group of other young adults with no high school qualifications. Not one adult with a moderate intellectual disability (defined as <50 IQ) had been in open employment and only 50 percent of those with mild disabilities had experienced some open employment. However, their job histories were different to the comparison group, and women were particularly disadvantaged. Richardson et al note the importance of basic literacy and numeracy skills in most jobs, and the expressed regret of many of these adults that they had not had further opportunities to develop these skills.

A British study (Freshwater and Leyden 1989) confirms the high unemployment rate for adults with at least a moderate intellectual disability who had attended special schools. They found 68 percent of their sample of 47 adults were unemployed, and 52 percent of this group had never had a job. Only four adults had fulltime work. Those who had been

employed had many changes of jobs, and redundancies were common. The adults themselves were "fed up" and over 70 percent felt that school "could have done more for them".

The general picture emerging from studies of school leavers in the 1980s is fairly negative, particularly for adults with a more marked intellectual disability. These results are also reflecting the outcomes of segregated educational provisions and a general lack of targeted transition programmes and adult employment services.

Studies of school leavers in the 1990s often reflect significant changes in school programmes and adult services. Some studies were specifically designed as evaluations of new programmes or services which had been designed to increase success in open employment.

Neubert, Tilson and Ianacone (1989) followed the progress of 66 young adults with learning disabilities (44%) and a mild intellectual disability (56%) who had graduated from a post secondary transition programme. The programme involved seven consecutive structured phases:

- initial client intake
- eight weeks' employability skills course
- two job "try-outs"
- structured job search support
- highly individualised competitive job placement with follow-up and support
- job clubs (to meet and share experiences)
- job change and advancement support.

Of the original 66 adults placed in work, 48 percent were in fulltime jobs and 52 percent part-time. Of the 74 percent who experienced job-related difficulties, most experienced task-related and/or work adjustment problems. Fifty-two percent of the sample changed jobs during the first year. The average time in the initial job, however, was 10 months. Most of the support required was during the first week of employment. This study demonstrates the importance of focussed employment training and on-going support necessary for many young adults with a mild disability. In the New Zealand context, many of these young adults may not even be referred to such services, or they may not exist in their area.

Affleck, Edgar, Levine and Kortering (1990) concluded from comparing their own results with older follow-up studies that:

> *… the most disturbing finding we made in reviewing the 'old' follow-up studies is that things have not changed in the past 50 years (p 323).*

Their study followed a large sample of mildly disabled and non-disabled students for a period of two and a half years after completing school, with data collection at six month intervals. The percentages of school leavers with an intellectual disability who were employed at each period ranged from 41-50 percent. Affleck et al see the first few years following school as a period of "floundering" for many young disabled adults, and note the importance of support and the need to restructure high school programmes for this group.

For adults with moderate and severe disabilities, the employment outcomes of later follow-up studies continued to be very poor. Haring and Lovett (1990), in a study of 58 young adults with an intellectual disability, found only six percent were competitively employed. However, none of the adults had received any organised supported employment services, as no such services existed at that time in that area. A further issue for these young adults was lack of independent mobility in the community – 45 percent relied on family or services for transport.

There is some evidence from later research that some aspects of employment status of adults with an intellectual disability improves some years **after** leaving school. Frank and Sitlington (1993) found that, in a sample of 322 adults with an intellectual disability, over a period of three years:

- they became more independent in living
- those employed increased the number of hours worked
- the number receiving "fringe benefits" increased
- their hourly wages increased.

However, there was no major improvement in the rate of paid employment, with 72 percent of the group employed fulltime or part-time. The degree of the intellectual disability was also not severe, ranging from "borderline" (not recognised in New Zealand) to "moderate". This study also found that the majority of these adults found their job through their self/family/friends networks, rather than through services for adults.

The results of a Scottish longitudinal study of adults with Down syndrome who had all been educated in special schools or units is less encouraging. In a six year study of the transition from school to adulthood, Thomson, Ward and Wishart (1995) found negligible placement in employment and lives of continuing dependency. From their own research and reviews of other studies, Thomson et al conclude that the six indicators of "successful transition to adulthood" for adults with an intellectual disability are:

- employment
- economic self-sufficiency
- personal independence
- social competence
- taking up an adult role in the home and/or society
- uptake of post-secondary education.

Adults with a mild intellectual disability are also at-risk of poor employment outcomes. Patton, Smith, Clark, Polloway, Edgar and Lee (1996) argue that this group may also experience inappropriate curricula and a lack of necessary supports in school and adulthood. Their major concerns with regard to this large group are:

- limited job opportunities
- poor general job skills
- an increasingly complex workplace demanding higher skills
- economic fluctuations and uncertainties

- possible financial disincentives for working
- continued use of sheltered employment models.

Patton et al stress the need for transition planning and services, and more post-secondary educational options. In terms of research, they call for more follow-up data on adult outcomes.

The need for follow-up data has been recognised by the National Longitudinal Study of Special Education Students in the USA. This study followed 8000 young adults for five years after high school, using multiple data collection strategies. The design also included a matched group of non-disabled young adults. Blackorby and Wagner (1996) report on a sample of 1,990 young adults. The results of this study give more general cause for optimism than most previous research. The general results showed:

- more people employed over time and mostly in fulltime work
- better rates of employment for men than women, in contrast to the general population (many women were fulltime wives or mothers)
- similar wage rates to "non-college youth" in the general population
- the rate of employment for adults with an intellectual disability rose from 25 percent to 37 percent, compared to 57 percent for the total group, and 69 percent for the non-disabled group; this rate was higher than that for adults who were deaf, and for adults with physical disabilities, however, it is still very similar to earlier studies
- similar wage rates to "non-college youth" in the general population, but evidence of real increases in earning power over time
- a widening gap in wage rates between genders.

The differences in male/female outcomes is confirmed in a review of research by Doren and Benz (1998). Women with an intellectual disability are less likely to be employed than men, and, if employed, they are more likely to:

- work in lower status occupations
- work fewer hours per week
- earn lower wages per hour
- work in jobs with few or no benefits
- experience greater job instability.

Doren and Benz note that the National Longitudinal Transition Study also found that women did not receive the same type or quality of vocational education and were more likely to be parents within two years of leaving school. They were also rated lower by their parents on functioning level and IQ scores. In the general literature on gender equity issues, the transition from adolescence to young adulthood is often marked by a decline in self-esteem and self-confidence, and differing expectations from teachers, family, and friends.

In their own study of 212 students with disabilities in their last high school year and first year post-school, Doren and Benz found only 47 percent of women employed, compared to 72 percent of young men. The major predictor variables (identified through logistic regression) related to this finding were:

- the number of jobs during school
- self esteem.

They also found that fewer females used their self-family-friend networks for job finding.

Other research has focussed specifically on gender inequity in work for people with a disability. Gwynne (1992) examined the results of a study of employment services across Australia. She identified adults with disabilities who were currently employed **and** had previously been in a sheltered workshop or activity centre. This data showed that two to three times more men were placed in jobs. The report gave the following reasons for the disparity:

- there were more male than female registrants
- women were more particular
- women have less experience
- women are not strong enough (p 44).

Evidence was also provided of sexism and discrimination within the sheltered workshop system, and in the high school programmes available at the time. Gwynne suggested that an Affirmative Action Plan was urgently needed for all vocational services for people with a disability.

Fulton and Sabornie (1994) reviewed studies of the employment outcomes of men and women with disabilities. All of these studies showed that women with disabilities were significantly disadvantaged compared to men with disabilities in regard to employment outcomes, in terms of: percentage employed; wage rates; hours worked; job retention; types of jobs; access to support services; job benefits; use of self-family-friend networks. Some studies also showed that factors which lead to less favourable employment status for women in general (eg, low aspirations, poor self-confidence, role conflicts, discrimination) operate also for women with a disability, along with additional factors such as family over-protection, high school experiences and training, and marriage/parenting. Fulton and Sabornie concluded that the equalisation of employment for women with disabilities should be a priority for high school, transition and employment services.

A recent study has examined gender differences in supported employment. Olson, Cioffi, Yovanoff and Mank (2000) surveyed 462 supported employees in the US, as part of the Oregon Natural Supports Research Project. There were no significant gender issues in: behavioural issues at work; severity of behaviours; age; race; or residential status. However, males were more likely to show aggressive behaviour to property or sexually inappropriate behaviour and poor hygiene than females. In terms of employment outcomes:

- men worked longer hours per week
- men earned higher monthly wages
- more women than men left their jobs voluntarily
- women were more likely to be employed in food service and clerical jobs
- men were more likely to be employed in custodial and janitorial jobs.

Olson et al concluded that the women with a disability in this study experienced typical gender disadvantages in terms of the types of jobs they held. Women with disabilities may also be disadvantaged in their access to income support (Mudrick 1988 cited in Olson et al 2000). They concluded:

> *The vocational support agency staff and the employers of women with disabilities are members of a society that views people with disabilities and women in general through a distorted lens, holding negative assumptions about the employability of both. These gender-biased and disability-biased assumptions directly impact women in supported employment (p 94).*

More recent research by Benz, Lindstrom and Yovanoff (2000) provides further evidence regarding predictors of employment for 709 young adults with a disability. Benz et al examined the outcomes of a "youth transition" programme in Oregon. The employment outcomes for these young adults were as follows:

- 35 percent were in fulltime employment
- 14 percent were in fulltime continuing education
- 21 percent were in part-time work and part-time education
- 9 percent were in part-time work only
- 21 percent were not in work or education.

Positive predictors were:

- graduation from high school
- one year or more in the Youth Transition programme
- having held two or more paid jobs
- completion of four or more transition goals.

Negative predictors involved the presence of "at risk" barriers.

Benz et al also examined the perceptions of the young adults themselves, using six focus groups to cover different communities and participants. The young adults described frustrations with traditional high school programmes, such as boredom and inability to do the work. The differences they valued in the special Youth Transition programme were:

- individualised, student-centred services
- consistent staff support, their willingness to listen and their availability
- staff persistence with the young people
- the programme's focus on their strengths, and how they had been helped to develop self-confidence.

Benz et al sum up these findings as showing the importance of "rigour, relevance, and relationships" in transition services for young adults.

Finally, a recent New Zealand report on a pilot supported employment programme provides useful, indicative data. Robinson, Bishop, and Woodman (2000) provide an

evaluation of a programme which began before the young people left school and continued on. They noted that less than 50 percent of the students were expected to find jobs during their first three years out of school. According to the 1996 Household Disability Survey, only 51 percent of people with a disability in the 15-24 year age group were employed (compared to 64.5% of the non-disabled population). They cite earlier research (Wilton et al 1988), which showed a declining rate of employment for adults with a mild intellectual disability since the late 1970s.

This particular programme for young people had developed out of a supported employment programme for adults with a disability. Robinson et al compared the outcomes for 13 school leavers with those of 24 older adults referred in the same year. The student group appeared to have more severe disabilities **and** had had no experience of paid work.

The programme involved extensive work in the transition phase, with almost as much time involved as in the actual job support. The outcomes were job offers for 12 of the 13 students (one job offer was turned down). The outcomes were 85 percent of the student group employed, compared to 39 percent of the adult group. The student group required much more time in career planning and more direct hours of input.

This project demonstrated far more positive employment outcomes than much of the literature suggests. Robinson et al attribute this success to the carefully planned, individualised transition phase and the attention to evidence-based practice in supported employment. They stress the need to begin employment and career planning for young adults with an intellectual disability, two years before leaving high school.

Summary

How do adults with an intellectual disability fare after leaving school? How many are in the workforce? The studies reviewed here show how any answers to this question are both time and context-bound. The answer must be "It depends". While individual characteristics are clearly relevant, it appears that other factors – type of high school programme, availability of transition services, labour market, social policies, availability of appropriate employment support services – may be more important.

Rates of employment in the follow-up studies of school leavers ranged from 0-72 percent, with the average rate being 37 percent. These varied findings illustrate the critical importance of relevant high school, transition, and employment programmes for young adults. Families' attitudes and support are yet another important influence on work outcomes.

CHAPTER FOUR

FAMILIES' CONTRIBUTIONS TO THE WORKING LIVES OF THEIR ADULT SONS AND DAUGHTERS

A previous review on Relationships for adults with an intellectual disability included an examination of the central role of families and some of the difficulties experienced by many parents in coping with their offspring's transition to adulthood (Mirfin-Veitch 2003). This review will therefore review some additional research which focuses more closely on families' attitudes towards employment for their sons and daughters, and some of the support roles they play.

Many of the advances in services for adults with an intellectual disability have been spearheaded by parents. For example, D'Agostino (1997) describes the Parent Alliance Employment Network Project in Illinois, which was begun in 1979 by parents who found few employment opportunities for their sons and daughters with an intellectual disability. In addition to this proactive role in service development, the support provided by families may contribute significantly to adults' job success.

Dixon and Reddacliff (2001) studied the role of families in the successful competitive employment of 15 young adults with a mild intellectual disability, aged 19 to 30 years. All except one adult were living with their parents. Information was gained from semi-structured interviews with the adults, and also from a few family members who sat in on interviews.

Most of the adults with an intellectual disability saw their families as highly supportive of them getting and keeping employment. The family characteristics observed in these families of successful employees were:

- **practical assistance:** families helped with daily tasks eg, laundry, and with job assistance such as transport, and initiating contacts with support agencies

- **moral support:** families provided a strong model of the work ethic, along with encouragement and rewards for work-related success

- **protection:** parents often provided protection from difficulties and concern about exploitation in the work place. They initiated contact when trouble arose and acted as advocates for their sons and daughters. They also often provided protection against risk and failure, for example, curtailing their other activities when they got a job

  There was also sometimes a "downside" to this protection, however, with some over-involvement in day-to-day decisions and social activities, and encouragement of unnecessary dependency eg, in daily living tasks, finances. Parents were sometimes unaware of some of their offsprings' competencies

- **family cohesion:** These families were characterised by strong family cohesion, with many family activities, and reciprocal contributions among family members. There was also typically a high level of involvement. On the other side, the adults

> with an intellectual disability did not appear to have out-of-work relationships with co-workers, and their own goals of greater independence in other areas of their lives were less likely to be encouraged than work goals.

Dixon and Reddacliff found that parents appeared to treat their adult sons and daughters more like younger people in areas **other than** work eg, living, recreation, social relationships. These were seen as areas "for the future". It was also clear that some families were frustrated at the amount of involvement they still had to have eg, advocacy, liaison. They concluded that more planning and collaboration with families is needed, and for adults without supportive families, alternative advocacy services may be needed.

An Australian study of work outcomes for Australian adults with an intellectual disability also shows the significance of the role played by parents and families. Clear and Mank (1990) studied the work outcomes of 24 adults with an intellectual disability in five different employment programmes and the contributions of different kinds of support and levels of assistance. Most of the adults relied primarily on their parents (62.5%) for advocacy and support. It was apparent from some reports, that when parental support was **not** available, the transition to work was often a difficult process (p 250). In terms of the actual amount of support time provided, the data showed that parents were involved, on average, more days per week and for a greater period of time than any other identified advocate (p 251).

While there is a scarcity of research on parental attitudes to employment for adults with an intellectual disability, some studies provide contrasting findings.

Hill, Seyfarth, Banks, Wehman and Orelove (1987) examined parental attitudes towards more "normal" employment outcomes for adults with an intellectual disability. This study took place within a context in USA of increasing opportunities for supported and competitive employment options for adults with an intellectual disability, but may be comparable to the current New Zealand context. Hill et al surveyed a carefully selected, representative sample of parents, with the final sample for analysis including 269 parents.

While the majority of parents agreed with "work should be a normal part of life for their son or daughter", they were largely satisfied with the status quo ie, mostly activity centres and sheltered workshops. Their attitudes were related, to some degree, to the severity of their son's or daughter's disability, but most expressed a negative or low interest in improved working conditions, such as increased wages. Thus there was a discrepancy between their perceptions of the importance of work and the perceived **un**importance of work outcomes. Also, there were no differences between the attitudes of parents of younger and older adults.

Hill et al concluded that:

> *Much more parent/professional communication is needed to improve parental expectations for the vocational potentials of their children who have intellectual disabilities…*
>
> *… parents will not accept the recent trend to change the status of the (intellectually disabled) adult from tax burden to taxpayer without many more assurances than are currently provided (p 22).*

Wehman, Moon, Everson, Wood, and Barcus (1988) also found that parental concerns were often an obstacle to job placement. They concluded that parents need detailed information to allay their uneasiness about the following issues:

- the "best interests" of the adult with an intellectual disability
- that promises to deliver help will be kept, particularly when the adult has negative experiences on the job
- money issues around losing benefits
- the danger of "letdown" when a job does not work out.

Wehman et al suggest that parents may need to see their son or daughter in the actual work setting, and that parents who **have** had successful experiences may be helpful to provide reassurance and information.

A New Zealand study by Westwood and Mitchell (1988), also found that parents often had low expectations and a lack of information. For example, 60 percent of parents did not know what kind of work their sons or daughters wanted or could expect. They were poorly informed about the role of the school and of post-school programmes, and only knew about activity centres and sheltered workshops.

A more recent study presented a contrasting picture of parental attitudes of mothers of young people with an intellectual disability. Lehmann and Baker (1995) interviewed 40 mothers of adolescents nearing high school completion. The attitudes of mothers of 20 young people with an intellectual disability were compared to 20 mothers of non-disabled young people in similar vocational-oriented programmes at high school. On the whole, attitudes towards living, work, and the social life of their children were remarkably similar. In the area of work, the mothers of adolescents with an intellectual disability had more specific ideas as to the types of jobs they expected for their children. They expected them to work at least half-time, with the help of supported employment programmes.

While there are methodological differences between the earlier US studies and the Lemann and Baker study, it is likely that the different findings largely reflect the growth of effective transition and supported employment programmes in USA during the intervening eight years. Parents' attitudes and expectations are likely to have changed as they have seen the reality of better support services and more adults with an intellectual disability succeeding in employment.

The entry of adults into supported employment also represents a critical transition for families, one which may occur later than for other families, and which may never be fully completed. Lustig and Thomas (1997) sought to understand why some families cope better than others with this transition.

Parents of 18 to 30 year olds whose sons or daughters were entering, or had recently entered supported employment, completed various measures of family functioning and stress. The study showed that similar family strengths (to the "normal" population) were related to family adaptation, for both mothers and fathers. What is probably of most relevance, however, is that some families appeared to be 'at risk' and Lustig and Thomas suggest that some families may need additional support through this "transition" in the

family lifecycle. Traditionally, family support services are focussed on parents of young children.

Kaplan (1993) believes that the relationship between families and adult services has not received the attention it deserves. Most parents have had to assume a very involved and active advocacy role when their children were going through school, and may have learned to be wary of professionals. They may also have learned to fear changes in services due to their struggles to obtain appropriate support for their children. Such attitudes may carry over to their interactions with adult services. Parents may feel excluded or usurped as adults with an intellectual disability turn more to staff for advice and support.

Staff in adult services can experience frustration at what is perceived to be family resistance to change and overprotection. Positive relationships among consumers, family, and staff are important to the work opportunities and achievements of adults with disabilities. Kaplan sees the ideal as follows:

> *When possible, the consumers should be the primary decision-makers, the staff members should be their daily support and instructors; and the family, their companions, roots, and a tie to the community (p 329).*

Kaplan sees the primary responsibility for developing positive relationships with families resting with management and senior staff in disability support services. She recommends that agencies should:

- set policy that supports strong agency-family-consumer relationships
- write job descriptions that clearly and specifically support the policy
- train supervisors to provide models and hold other staff accountable
- provide line-staff training on family experiences and issues
- provide orientation and training for families
- prepare a written family guide
- provide opportunities for joint planning, collaboration, and problem-solving among staff, consumers, and families (p 330-1).

Callahan and Garner (1997) also provide a useful set of recommendations "for employment professionals to follow in the delicate process of encouraging family involvement while encouraging independence" (p 55). These detailed recommendations are based on an approach which seeks to empower and include families. The areas of involvement are identified as:

- involvement in planning activities
- involvement in decision making
- the family as a source for employment leads
- the family as a source of supports (p 62-4).

Summary

Family support makes a very important contribution to the work outcomes of adults with an intellectual disability. The types of support families can provide include emotional, practical, and advocacy support, and this support is appreciated by the adults themselves, who often still live with their parents.

On the other hand, families can be a barrier to attaining successful work by adults with an intellectual disability. Families can sometimes be over-protective and discouraging of independence. However, they also lack adequate information about opportunities and what their sons and daughters can do. Even when families encourage their offspring to work, they may be less encouraging of other adult roles, such as relationships. Many families are satisfied with sheltered employment as "work", and see no value in changing services to support people in paid jobs in the community.

Parents of young people leaving school today are more likely to have higher work expectations for their sons and daughters with an intellectual disability.

The transition to adulthood of young people with an intellectual disability can be a difficult time for families, but is often one in which support for families is lacking. Families may also experience difficulties in relating to adult services, and staff may need to be particularly sensitive to the differing roles they fulfil and that families provide – for the adults with an intellectual disability.

CHAPTER FIVE

EMPLOYERS' ATTITUDES AND CHARACTERISTICS

With increasing emphasis from the 1980s on paid employment for adults with an intellectual disability, employers' attitudes have been the focus of research into barriers to employment.

An early study by Shafer, Hill, Seyfarth and Wehman (1987) surveyed 483 employers who all employed at least one person who had an intellectual disability. Responses were received from 261 employers (54%). Employers were generally satisfied with their employees and tended to justify taking on the employee as "deserving the opportunity to work" (p 307). However, employers who received supported employment services were more satisfied than those who only received job placement or no known services. A significant number of respondents were not aware that at least one of their employees had an intellectual disability.

Employers who received supported employment services provided higher evaluations of their workers on 11 out of 12 performance indicators. They were also more likely to use tax incentives and to evaluate their disabled employees more favourably.

Employers' perceptions of workers with an intellectual disability emphasised positive traits of dependability, trustworthiness, and loyalty. On the less positive side, they mentioned that such employees were slower to learn and perform work tasks, and more in need of supervision.

Shafer et al concluded that:

> *these results suggest that with appropriate support services, workers who are moderately or severely retarded may be able to function at a reasonably high level of competence (p 309).*

An early New Zealand study also surveyed employers. Wilton et al (1988) surveyed a representative sample of 32 employers in the West Auckland region to identify employment opportunities for school leavers with a mild intellectual disability. A majority (56%) of employers said they would consider employing a young adult with a mild intellectual disability, when a vacancy arose, but only a few employers expected to have such a vacancy that year. This study found more positive responses from large employers, who were also more likely to have disabled employees.

Are employer organisational characteristics predictive of their hiring practices? In a survey of 1000 randomly selected employers, Craig and Boyd (1990) found 64 percent of the 671 respondents reported employing 166 "handicapped people". Proportionally more large employers (more than 100 employees) had employees with disabilities. However, in real numbers more small employers were in this category. Overall, this survey found that "handicapped" people were "most often employed by large employers in urban areas who are engaged in the food service industry" (p 42).

A later study focussed on large employers was undertaken by Levy, Jessop, Rimmerman and Levy (1992) who surveyed 1,140 Fortune 500 industrial and service organisations. The median number of employees in these organisations was 7,500. This study focussed on attitudes to people with severe disabilities (1% of the population) and their perceived employability. Among the 34 surveys returned, they found generally favourable employer attitudes, with the most positive attitudes among those employers who had had contact with people with disabilities **in the workplace.** Having a disability oneself or a family member with a disability were **not** found to be key factors. Unfortunately, the low return of survey questionnaires limits the value of these findings.

A study in Hong Kong (Tse 1994) confirms the importance of employers' actual experiences of employing people with disabilities. This study sought 38 employers' ratings of work-related attributes among employees with a mild intellectual disability. Among 25 specific work-related attributes, employers rated these employees as exceeding expectations in seven attributes, fulfilling expectations in 13, and falling below expectations in only five attributes. Employees were rated as having a good record of work safety, reliable, well-motivated and honest. The four areas in which employees were rated as "low, or poor" were: appearance, education, work experience, and personality – all attributes that might be seen as largely outside of the individual's control. Even though these disabled employees' work performance was generally evaluated positively, they were paid, on average, 30 percent less than non-disabled employees holding the same jobs.

Employers' perceptions of their employees who have disabilities is clearly an important predictor of their attitudes towards employing other people with a disability. Shafer, Kregel, Banks, and Hill (1988) analysed written employer evaluations of 125 workers with an intellectual disability. The three most significant factors related to these workers retaining their jobs were: attendance, punctuality, and consistency in job performance. Employer evaluations were not related to workers' severity of disability. Shafer et al suggest that, for some employment settings such as entry-level service positions:

> *employers may be more concerned with the dependability and loyalty of their workers and in fact may be willing to lower other performance standards in exchange for workers who consistently arrive at work and who display relatively low turnover (p 389).*

A later study confirms some of these influences on employers' attitudes to hiring adults with an intellectual disability. Sitlington and Easterday (1992) examined the effect of 10 incentives on the willingness of 84 employers to hire a worker with an intellectual disability. The four most important incentives to employers were:

- probability of regular attendance
- ongoing availability of a person to call for assistance
- high probability of long-term employment
- availability of a person for on-site training (p 79).

Financial incentives were ranked as least important by these employers.

Employer attitudes may also be influenced by their own cultural values. For example, in a New Zealand study (Reid and Bray 1997), the three employers that were interviewed

emphasised their strong belief in "giving a person a chance" (p 94). These employers were also willing to provide on-the-job training, and expected that, eventually, workers would be able to do their job independently.

Later studies have provided more detailed information with implications for vocational services. For example, Nietupski, Hamre-Nietupski, Song VanderHart and Fishback (1996) undertook research following a statewide supported employment systems change project. Four types of businesses were selected for study: banks, credit unions, grocery stores and retail stores. These businesses were chosen to represent the Iowa economy and to reflect those which had been targeted in the systems change project. From a random sample of 200 organisations, 98 surveys were returned. Organisations who had hired supported employees were compared with those who had not. Significantly more positive attitudes were found in organisations with supported employees, and also in large businesses. The benefits perceived by employers were:

- employee dedication
- community image
- personal satisfaction (of the employer).

The concerns expressed by employers included:

- the extra training and supervision required
- lack of necessary job skills
- work quality – (but only expressed by those who had **not** hired supported employees).

Nietupski et al provide a number of suggestions for educators and supported employment agencies arising from this research. These include:

- the need to emphasise the perception of disabled people as dedicated employees
- stressing the positive experience of other employers regarding work quality
- the need to overcome the prevailing perceptions of lack of job skills and training demands
- using "recognition" methods to promote community image
- using referrals from other satisfied employers who had experienced supported employment services
- the need for early, intensive work experience across a variety of settings during high school and transition services
- targeting jobs based on a match between consumer and employer
- better provision of support.

The common findings of previous studies of employer attitudes were confirmed in a study of 120 corporate executives in Israel (Rimmerman 1998). The three key variables associated with positive attitudes towards employing adults with an intellectual disability were:

- previous contact
- hiring experience
- large organisations.

Supported employment providers may also need to consider the employer acceptability (or otherwise) of certain training strategies. Given the emphasis on behavioural training techniques in the early supported employment programmes, this issue was investigated in 1981 (Menchetti, Rusch and Lamson 1981). This study showed that some techniques were acceptable, even though they were different to the methods used to train other workers. However, some behavioural strategies used to change or manage inappropriate behaviours were **not** acceptable. Also, some reinforcement strategies, eg, tokens, were unacceptable. Menchetti et al point out that acceptability can vary depending on the type of job, and the particular employer and work culture of each setting.

A more recent study of employers' contributions to the quality of supported employment outcomes is provided by Unger (1999). Unger notes that employers provide many types of support to their non-disabled employees, and the needs of disabled employees may not be very dissimilar. Also, there may be external sources of workplace support that are unfamiliar to employers.

Under the Americans with Disabilities Act, employers are responsible for providing "reasonable accommodations" to enable people with a disability to perform their jobs. Available evidence shows that the percentage of employers "making accommodations" increased significantly from 1993 to 1995, with the typical cost being only about US$200.

Unger collected data from 53 businesses, the majority of which employed less than 100 employees. The employers (and consumers) surveyed identified 31 different types of support needs which were then categorised into four areas:

- employee training (the most frequent)
- career advancement
- employee benefit
- workplace culture.

To meet the identified training needs, most employees paired the new worker with experienced co-workers who undertook the training. Other methods used were: supervisor instruction, orientation meetings, and company videos. Employers did not usually see the employment specialist/job coach as the primary provider of training support.

On the whole, Unger found that employers were providing a range of workplace supports (accommodations) which went beyond the legal requirements. She saw these results as very encouraging for the future of employment for adults with a disability, particularly as these were small businesses with fewer resources than large organisations. She concluded:

> *The employment of people with disabilities is evolving, due in part to more favorable employer attitudes toward individuals with disabilities in the workforce, workplace cultures that embrace workforce diversity, assistive technology, progressive laws designed to ease the entry of people with disabilities into the workforce, and the perseverance of individuals with disabilities (p 191-2).*

The issue of a supportive workplace culture was further explored in a study by Butterworth, Hagner, Helm, and Whelley (2000). They used participant observation and

semi-structured interviews with workers to investigate workplace culture. They compared four work settings with the highest scores on a measure of integration with four settings with the lowest scores. The participants were eight young adults with an intellectual disability who worked in these settings.

The analysis of the data identified four workplace characteristics that were clearly related to workplace interaction and support.

- People in the workplace have relationships in multiple contexts, both inside and out of the work setting.
- The workplace provides identified opportunities for social interaction eg, gathering for lunch.
- The employer uses a management style that shows personal concern for and interest in employees, and fosters team-building.
- Individual workers have an "interdependent" job design that involves interaction and shared job responsibilities with co-workers (p 348).

The promotion of a positive workplace culture is a critical role for employers.

Summary

While the lay perception may be that the biggest barrier to employment for adults with an intellectual disability is employers' negative attitudes – this is not generally supported by the research evidence.

Positive attitudes are more likely when employers have had experience of employing a person with an intellectual disability, particularly when the employer also receives supported employment services.

Employers in large organisations are more likely to have positive attitudes than those in small organisations.

Employers often rate employees with disabilities as having good work attitudes and characteristics eg, reliability, even though work productivity may be seen as lower and the employee needs more training and supervision.

Providers of supported employment need to consider whether their training strategies will be acceptable in specific work settings. It is important to consider the range of typical supports provided to other employees, and the important contributions of employers to a positive workplace culture.

CHAPTER SIX

SUPPORTED EMPLOYMENT: TRENDS AND ISSUES

In terms of international developments, Supported Employment, as a model of service, has been found to produce the most successful work outcomes for adults with an intellectual disability. However, it is still in the process of development and this is seen in the continuing research and academic publications which have been evident from the 1980s. This review cannot possibly cover this large body of research, but will consider some of the research which was most accessible, and refer to some recent research reviews. This chapter will divide the review into aspects of supported employment, reflecting areas of concern and on-going research activity.

Brief history and outcomes of supported employment

Supported employment has evolved from earlier approaches which focussed on training and supporting **groups** of adults with an intellectual disability in real work settings, often industrial or manufacturing work. The early models were also typically University-based research and demonstration models of service, and thus included a strong research component and access to resources and expertise. The University of Oregon was the source of some of these early developments. For example, Rhodes and Valenta (1985) describe an "enclave" or group model of supported employment in which six adults with a severe intellectual disability were employed within a large electronics firm. Because of the need for intensive training and supervision, a special production line for the supported workers was established within the normal space and flow of the factory. The work task involved subassemblies of parts required for heart defibrillators. Supported employees worked the same 10 hour day and four day week as other employees. Earnings were based on an hourly rate tied to productivity, and the same work benefits as other employees were also provided eg, holiday pay, sick leave etc.

The primary work supervisor was trained on company procedures etc **and** had expertise in behaviourally based skills training. Two of the original eight supported employees were not successful long-term, but the other six workers showed positive work outcomes in terms of:

- low absenteeism
- minimal injury rates
- at or above 50 percent 'normal' productivity after one year
- a steep decline in the public costs of the programme
- positive social contacts with other employees, both at work and outside of work.

The use of an "enclave" model of supported employment is also reported by Warth (1990) in Australia. While this type of group model is less favoured in contemporary research, it is clearly still being used and **may** provide a desired option for some individuals. This example was also based on wages tied to productivity, and a group of six employees working at the Royal Australian Mint, which employed over 240 employees. The hours of work were the same as other employees. All supported employees earned significantly more than they had in the sheltered workshop, and there

were significant savings in social security benefits. Other social benefits and increased self-esteem and self-confidence were also reported. Warth notes that the project showed that at least three of the group could work in individual supported employment sites. Unfortunately this particular example was only a temporary contract, and while two further contracts developed out of it, the results were **not** permanent employment for the workers involved.

A contrasting early model focussing on competitive employment for adults with moderate and severe intellectual disabilities is reported by Wehman and Kregel (1985). In this report, "competitive" meant earning at least the minimum wage. This "supported work" approach has strong similarities to the current supported employment model promoted by ASENZ (the Association for Supported Employment in New Zealand). Clients receive on-going support throughout their employment, within the various stages of:

- highly structured job placement
- job site training and advocacy
- ongoing monitoring
- a systematic approach to follow up and retention (Table 1, p 5).

Wehman and Kregel note the following implications of moving to a goal of employment for adults with an intellectual disability.

- Schools will need to make a clear commitment to train students for competitive employment.
- Schools will need to use integrated services, functional curricula, and community-based training.
- Training programmes are needed to train specialists in supported employment practices.
- Financial incentives are needed to encourage the placement of adults with an intellectual disability into competitive employment.
- Vocational services should be encouraged to use a supported work model.
- More funds are needed for training that is linked to jobs in competitive employment.
- Staff in vocational services need to be training in job placement, jobsite behavioural training and follow-up strategies.
- Demonstration programmes are needed within community-based adult services.

Similar demonstration projects were also reported in other countries during the 1980s. For example, Tuckerman (1987) described a "supported competitive employment" project in Sydney for adults with an intellectual disability.

While supported employment services have developed in all Western countries, there has been concern about the ways in which the initial 'models' have been changed, and the variety of vocational programmes which have been titled 'supported employment' (Bennie 1996).

Trach and Rusch (1989) evaluated 33 supported employment programmes in Illinois, developed by these agencies as new services, in addition to traditional services. Services were evaluated in terms of their degree of implementation of 28 characteristics of

supported employment identified from a review of research. Outcomes and demographic data for all clients were also collected. The results showed correlations between IQ, hourly wage, and monthly wage, and a significant direct relationship between the hourly wage and the hours spent in job development (p 137). It was also clear that fewer components of the programme were needed when placing less disabled individuals into jobs. Furthermore, as more hours were spent in job development, the total evaluation score increased ie, the programmes implemented more of the 28 characteristics in the "Degree of Implementation" model. Trach and Rusch suggest that supported employment was sometimes being provided for people with milder disabilities who did not really need that type of intensive service.

A different evaluation approach was used by Freeze, Kueneman, Frankel, Mahon and Neilsen (1999). They investigated how successful services had been in addressing the systemic, attitudinal, and procedural barriers to the employment of people with disabilities in Canada. The project involved three approaches: a population survey of Winnepeg households, interviews with employment services experts (including 10 consumers) and interviews with 39 people with a disability and people involved with them. These individuals were all in employment.

The public survey showed that there was strong public support for government assistance for people with a disability, particularly those with a physical or intellectual disability. There was also strong support for the provision of support in community settings. The "experts" interviewed noted a major barrier to work as being lack of opportunities for appropriate employment training for everyone who needed it. Some people believed that the passive attitudes or lack of "work ethic" of some people with a disability themselves were often a barrier to employment. The realities of the labour market were seen as significant barriers, as well as disincentives to work for people with a disability. Employer attitudes were also noted as major barriers, as evidenced by employers' actions (or inactions), rather than their expressed attitudes which often appeared positive.

Overall, the experts interviewed believed that supported employment was the most effective route to the employment of people with a disability. An array of legislative and policy measures (eg, employment equity legislation, affirmative action) were also noted as helpful. Sheltered employment was also criticised for not providing real jobs and not leading to employment in the community.

The people with a disability who were interviewed described many positive outcomes from their successful employment, including greater self-esteem, greater income and what it meant, improvement in their physical well-being, better social life and independence, and greater self-confidence. They also displayed a strong work ethic, and felt supported by their families and employers.

Direct comparisons between the outcomes of sheltered workshops and supported employment confirm the benefits found by Freeze et al (1999). Goldberg, McLean, LaVigne, Fratolillo and Sullivan (1990) compared the employment outcomes of two groups of adults with an intellectual disability who had been randomly assigned to supported employment and sheltered workshop services.

This study showed that those adults in the supported employment programme were more likely to get a job, than those in sheltered work. Positive outcomes have also been

reported in a study by Reid, Green and Parsons (1998) of adults with multiple severe disabilities. In this study, the same four adults were involved in the two types of programmes, on alternating weeks. Systematic observations of their behaviour in the two programmes showed:

- they were more alert and active, and more involved in purposeful activity in supported work
- two of the adults showed more evidence of happiness during supported work; no differences were apparent for the other two adults.

While considerable research has demonstrated the success of supported employment for adults with an intellectual disability, some research has noted the continuing low numbers of adults with severe disabilities who are being included in supported employment. Schalock, McGaughey and Kiernan (1989) conducted two national employment surveys to document outcomes from different vocational services, during the years 1984-1986. The general conclusions from this survey were:

- the majority of adults with an intellectual disability were in sheltered workshops, although there was a trend towards moving into employment in the community
- higher incomes were associated with less severe disability and competitive employment
- most jobs were in the food service, building service, and assembly industry
- competitive employment was the most common placement, followed by supported employment and transitional employment
- the average age of persons placed was 28 to 30 years, with slightly younger persons placed into competitive employment.

Kregel and Wehman (1989), in an analysis of the employment histories of 1,411 adults in supported employment, found that only 8 percent of this group had a severe or profound disability. This was despite the fact that supported employment had been initially developed **for** people with the most severe disabilities, who were not considered eligible for other vocational services. Kregel and Wehman found that of the 1,147 adults with an intellectual disability in supported employment, only 10 percent had a severe or profound disability. Adults from this group were also two times more likely to be placed into 'enclaves' (groups of workers) rather than in individual placements. Forty-five percent of this group had experienced institutionalisation, and were less likely to have work-related skills before entering supported employment. Kregel and Wehman concluded that, in general, supported employment programmes were **not** serving the entire range of individuals for whom supported employment was intended. They suggest that stronger incentives may be needed to encourage providers to meet the needs of this severely disadvantaged group.

Finally, a more recent US survey (Olney and Kennedy 2001) found that nearly 60 percent of adults with an intellectual disability were still in sheltered workshops rather than supported employment. This survey related to the years 1994-1995, and covered a population-based sample of all adults with an intellectual disability. They concluded:

> *Originally conceptualized as a stepping stone to employment, sheltered employment has become, and continues to be, an end in itself for many (p 38).*

The major difference between supported employment and other vocational services is the ongoing nature of the support provided "on the job", for "as long as it takes". This type of extended support has also been the focus of research.

The provision of extended support

While an important component of supported employment has always been payment for work, there were early proponents who saw this as a barrier for some people with a severe disability. For example, Brown, Shiraga, York, Kessler, Strohm, Rogan, Sweet, Zanella, Van Deventer and Loomis (1984) argued strongly for a period of "extended training" for some adults **within** an integrated work setting **before** requiring a wage. Brown et al argued that there were other important values and outcomes of real work which were more important than direct pay, namely integration and the performance of meaningful work. They claimed that if the primary requirement was pay, many people with a severe disability would never get the chance to work in integrated employment settings. Brown et al asserted that some people with severe disabilities require an extended training period "on the job" before they could reach a reimbursable level of productivity, but they still benefited in many important ways from this opportunity. They suggested the following conditions should be met for this "extended training" option:

- that the work performed is meaningful
- that the level of productivity is less than 25% of that expected of other employees
- that a careful plan is developed, including the criteria for movement to direct pay for the work
- that continuous training on-the-job is provided
- that the plan is reviewed twice a year
- that careful protection of the person's rights is in place, to avoid exploitation.

Brown et al pointed out that only a few adults should qualify for this option, but its inclusion would remove a barrier to integrated work for some adults with a very severe intellectual disability who learn very slowly. The ultimate goal, however, for **all** adults with an intellectual disability, would be direct pay for productive work.

Whether long-term training and support is associated with paid or unpaid, integrated employment, there is no argument about the necessity of such support. Renzaglia, Wheeler, Hanson, and Miller (1991) provided an evaluation of the "follow along" or extended support component of a programme for a young man with a moderate level of intellectual disability. This extended support offers problem-solving, prevention of difficulties, maintenance of skills, and retraining, where necessary. The support will vary in its extent and intensity over time. Even though the young man had been in the job for three years, an in-depth assessment of his performance on all the tasks involved showed areas in which his performance was below an acceptable level. Systematic instruction was then introduced to retrain the young man in these parts of his job. The outcome of this training was that he was able to meet the skills required for his Civil Service position. This type of long term support enables an individualised approach which focuses on the needs of each individual and the demands of the particular job.

Ongoing support is also an essential part of career development for adults with an intellectual disability. In the general population, it is assumed that changing jobs is an

integral part of career development, but for adults with an intellectual disability it is often seen as failure. Pumpian, Fisher, Certo, and Smalley (1997) noted the problems in policies and regulations which are designed to achieve "case closure" once a person is successfully working in a paid job. However, high turnover rates in supported employment are relatively common, and often part of the type of part-time or temporary jobs involved. These researchers argued that ongoing support services "need to be proactive and anticipate the natural movement within and between jobs (p 40)". They explain:

> *Few workers establish job stability without years of job exploration, job experience, career development, and multiple job changes… Yet, workers with disabilities are expected to demonstrate job stability without similar years of exploration, experience and change. Then, if they do not meet this unrealistic standard, their very employability is questioned (p 40).*

In view of the fact that job change should be expected as an ordinary part of most people's lives, **and** because adults with an intellectual disability need support to find jobs and succeed in them, ongoing support is essential in order to provide proactive career development rather than reactive interventions after the person has left the job. Pumpian et al call for supported employment providers to be more familiar with theories, models, and research in the area of career development, career counselling and career programmes. They believe that:

> *A system that is responsive to the ongoing needs and wants of its consumers for lifelong career and job change will require a more sophisticated and varied set of supports along with a wider number of support providers (p 46).*

An expanded supported employment model would reflect typical career development and job mobility in the general population (p 47).

While job changes are certainly a typical pattern for most people, there has been a justifiable concern to avoid job dismissal and the negative experiences and feelings that would usually be part of this situation. Why do some people with an intellectual disability lose their jobs?

Salzberg, Lignugaris/Kraft and McCuller (1988) reviewed the available research on job loss among adults with an intellectual disability. This review covered a period when the extent of supported employment services was still limited. They concluded that reasons for job loss were situated in both social and non-social areas and included factors such as:

- attendance and punctuality
- task-production (eg, poor quality and rate of work)
- social skill deficits (eg, not following instructions)
- personal/social inadequacies (eg, bizarre behaviour).

Salzberg et al note that the job retention of adults with an intellectual disability compares favourably with studies of other workers in the same type of jobs. However they suggest that there are clearly areas for improvement in job retention, which would be more cost-effective (ie, provide benefits in cost and for workers) to avoid job dismissal.

Shafer, Banks and Kregel (1991) analysed the employment retention and replacement needs of 302 adults placed into supported employment. After two years, 30 percent were still employed in their original jobs, 20 percent were in other jobs, and over 31 percent had lost their jobs and were waiting to access supported employment services.

There was no significant relationship between employees' level of intellectual disability and their employment status. While Shafer et al note that career movement levels were comparable to other employees in entry-level jobs, they found that the majority of these employees with an intellectual disability experienced employer-initiated career movement in the form of terminations and lay-offs.

Another measure of job retention is to measure the total proportion of individuals who are employed at one point in time. This measure yielded retention rates of 61.2 percent for 12 months, and 53.4 percent for 24 months – substantially higher than retention only in the original job. This measure also recognises the needs of individuals who do change jobs.

A further important finding in this study was that 19 percent of the groups (at 24 months) were routinely "discharged" from supported employment only to be re-admitted and placed into another job within a brief period of time. More effective ongoing support would respond to the changing support needs of individuals over time. Given that initial placement and training costs are usually the largest portion of the costs, avoidance of unnecessary or unwanted job changes would also be more cost-effective.

Schalock and Genung (1993) report on a 15 year follow-up study of 85 adults with an intellectual disability who had been placed into independent housing and competitive employment. In terms of employment status, of the 50 people receiving no services, 70 percent were still employed in a competitive job, 14 percent were homemakers, and 16 percent were unemployed. Of those still receiving services, only 9 percent were still in competitive jobs, but 46 percent were in supported employment. Only 9 percent of this group were unemployed, and 36 percent were homemakers. Although this particular group were, on the whole, less disabled than current groups using services, the study suggests that even when individuals are placed into more independent living or work situations, about 20-25 percent are likely to need ongoing support.

Providing ongoing or extended employment support raises a number of implementation and funding issues. Supported employment providers have to place new people into jobs while still supporting previous clients in their jobs. West, Johnson, Cone, Hernandez and Revell (1998) surveyed a sample of 345 providers who were funded to provide extended services.

In most states in the US, funding for the ongoing part of supported employment funding has had to come from "non-vocational" funding, with the need to access funding from a variety of sources. West et al examined: the scope and type of services provided in the "extended" phase; funding sources and how these were accessed; and the impact of funding sources on service quality. The data showed that ongoing support was provided, on average, for 57 percent of the clients, usually by the employment specialist/job coach. However, only 40 percent of these clients received more than the minimally required support of two contacts per month.

Funding categories fell into three types: fee for service agreements; contractual or slot-based agreements; and 'other' funding methods. It appeared that a fixed hourly rate type of funding was least supportive of consumer choice, **and** was more likely to discourage movement from segregated services to community-based employment. Thus the funding method may present financial disincentives for providers to help individuals who want to make job changes. West et al also suggest that supported employment providers may be under-using 'natural' support networks in the workplace to meet some of the extended support needs of adults with an intellectual disability. The use of 'natural supports' continues to be the subject of extensive research, and will be reviewed in a later section. A further important characteristic of supported employment is the critical role of staff.

Staff roles in supported employment

The development of supported employment called for new staff skills and expertise which had not been so essential in sheltered employment and day activity programmes. Furthermore because of the fact that the new models began in University demonstration programmes with an emphasis on behaviourally based training approaches, "employment specialists" were seen as essential for successful outcomes.

Kregel, Hill and Banks (1988) analysed the use of employment specialist or "job coach" intervention time in early supported employment programmes over an eight year period. Intervention time was seen as a measure of the **intensity** of services provided. It was defined as "all activities that are designed to enable consumers to obtain, learn, perform, or maintain a job (p 210)". The consumers in this study were 51 adults with an intellectual disability who had been placed in paid work from 1979-1987. This sample represented the population of 245 individuals on all key variables. Detailed and verified data on intervention time had been kept by supported employment staff over the eight year period.

The analysis of this body of data showed that:

- the average weekly intervention time was 3.1 hours, but during the first four weeks on the job, consumers received an average of 86.8 hours of intervention time
- after the first 12 weeks, the amount of time levelled off to less than an hour a week
- during the first week of employment, the amount of intervention time was greater than the number of hours consumers worked
- adults with a moderate/severe intellectual disability did **not** require significantly more first year intervention time than did those with a mild/borderline intellectual disability.

These results have implications for the funding and implementation of supported employment programmes, but it is important to note that this study involved a well-established programme, probably employing highly trained staff. What sorts of qualifications were characteristic of staff at that time?

Winking, Trach, Rush, and Tines (1989) surveyed 31 supported employment providers in Illinois to examine the educational background, experience, and related employment variables of staff working in the position of employment specialist/job coach.

The **desired** qualifications included:

- a bachelor's degree in a related field
- experience with adults with a disability
- business experience.

The actual characteristics of 144 employment specialists did not always match the desired qualifications:

- 34 percent had a relevant bachelor's degree (4 years)
- 10 percent had a degree in an unrelated field
- 9 percent had some college-level education
- 5 percent had a master's degree
- 32 percent had only a high school diploma
- 57 percent had previous experience with people with disabilities
- 28 percent had business experience.

Salary levels were low, and turnover rates were high (ie, two people hired for every position), with a significant number of resignations due to money. It was clear that the salary level did not reflect the professional responsibilities of the position.

Winking et al also found that despite the differences in job responsibilities between employment specialists and staff working in sheltered workshops, the majority of agencies paid all staff on the same scale. These findings have significant implications for the quality and consistency of the supported employment services.

Another study of the training needs and backgrounds of supported employment staff confirms this general picture. Everson (1991) surveyed 519 staff in 142 supported employment programmes. She found that these staff were typically young women who were highly educated but poorly paid. They came from a variety of previous jobs, with over half of the managers having no previous experience in supported employment. The top five training needs identified by managers were:

- staff supervision techniques
- knowledge of job modifications/rehabilitation technology
- programme evaluation techniques
- client behaviour management techniques
- client reinforcement techniques (p 141).

The top training needs for job coaches were:

- social security and medical coverage
- client behaviour management techniques
- client reinforcement techniques
- techniques to promote integration.

While almost all staff had received some training in supported employment, this was often minimal, and staff expressed a preference for training in the form of "expert" technical assistance ie, on-site consultation and problem-solving.

A more recent Australian study confirms the need for training that meets the changing and multiple roles of supported employment staff. Ford and Ford (1998) surveyed 21 supported employment programme managers to identify their priorities for training and support. In contrast to the US studies, the majority of these programme managers were male and aged between 20 and 49 years. Few had ever been employed previously in supported employment. Only one-third had a bachelor's degree, but these staff were also critical of the relevance and adequacy of their tertiary study.

Most of their training and information came from reading, attending workshops and conferences, and from on-site technical assistance. A few people mentioned the value of networking with other programme managers. The five highest priority needs for these managers were:

- bidding for job contracts (many of these programmes used a group model of supported employment)
- generating programme funds
- using standardised vocational assessments
- techniques for programme evaluation
- staff supervision.

These managers also identified technical assistance as the most preferred training option, with its practical focus and location in the real context in which the programme operated. Professional isolation was expressed by managers working in rural areas.

Buckley and Mank (1994) identified changes in understanding organisational performance with a growing emphasis on quality and quality improvement. They believed that training and technical assistance for supported employment staff needed to reflect this new orientation. Performance problems in an organisation are typically related to other issues (eg, information, resources, incentives) than training needs. This fact explains why training often appears out-of-context and not directly relevant to the challenges facing staff working in supported employment. The three major components of a quality approach, according to Buckley and Mank are:

- an organisations specific **mission** or statement of purpose
- **accomplishments** that are specific to the organisation
- **measures** that are specific to each accomplishment (p 226).

Buckley and Mank note that, in this approach, teams of staff are best able to identify their own training needs, and also to recognise when training is **not** the appropriate response to problems (p 226). The critical roles for providers of training and technical assistance then become:

- relationship builders
- facilitators

- brokers of assistance
- information specialists.

Both the training provider **and** each organisation involved should be responsible for identifying the most appropriate training needed to improve service quality.

How do employers perceive the activities provided by job coaches/employment specialists? Ward, Dowrick and Weyland (1993) studied the actual activities performed by job coaches and how important these were to employer satisfaction. They found that both employers **and** job coaches rated their activities as important. Of particular importance were:

- regularly seeking feedback about the employee's job performance
- impromptu checkups
- providing additional supervision when needed.

Other valued activities included:

- assisting in clarifying work schedules
- mediating interpersonal relationships with co-workers
- assisting with negotiating benefits and compensation
- providing information about non-work issues that might affect the job
- solving safety and health concerns
- providing 'spot' training'
- increasing speed and efficiency
- training to increase the breadth of duties
- assisting co-workers to provide support.

As supported employment has become more widespread, additional roles or tasks have been the focus of research. Culver, Spencer and Gliner (1990) explored the role of "job developers" ie, actually developing new or adapted jobs to provide employment opportunities for adults with an intellectual disability. They note that the success of job developers is highly variable and difficult to measure. Culver et al found that success in obtaining job placements was related to the cumulative effects of:

- use of specific **in**formal marketing activities (most important)
- time allocated to job development activities
- participation in specific client focussed assessment activities
- **in**frequent use of unpaid trial job placements
- gender of the job developer (negligible effect, but women were marginally more effective than men).

However, these variables only accounted for 33 percent of the variance in job placement. Future research is necessary to identify other predictive variables.

Another type of staff role which has received less research attention is the provision of personal assistance services to supported employees. "Personal assistance" refers to assistance from another person with activities of daily living" (eg, personal hygiene; mobility). Turner, Barcus, West and Revell (1999) report on research on the experiences

of people with a disability who use personal assistance in their work setting. They note previous feedback on the need for more consumer control of this type of personal service. Two contrasting focus groups of people with a disability were recruited for this study, one group who had no experience in managing their own care, and a second group who used or provided personal assistance in the workplace. The focus group discussions identified various personal duties (eg, toileting, grooming) and job function duties (eg, making telephone calls, reading documents) undertaken by personal assistants.

The focus group discussions showed the wide variety of needs for personal assistance, from simple tasks to tasks requiring complex knowledge and skills. Another outcome was the following consensus definition:

> *Personal assistance services in the workplace are services provided to an employee with a disability by a personal assistant to enable the employee to perform the essential duties of a job more efficiently (p 154).*

The second phase of the study involved a survey of staff in 400 Centres for Independent Living (CILS). The main issues which emerged were the difficulties in accessing funding for **work**-related personal assistance, locating providers of personal assistance, and difficulties in working with agencies (p 155). This study identified some of the significant barriers to employment faced by adults with a disability who have significant needs for personal assistance.

In addition to the need for **more** assistance, the issue of **reducing** direct assistance to supported employees has also been the focus of research. Research by Neufeldt, Sandys, Fuchs, and Logan (1999) which examined supported employment programmes in Canada, found that job coaches experienced the fading out process as stressful. Most job coaches build up close relationships with supported employees, and this finding illustrates the need to consider the management of these relationships in terms of training and also professional supervision. Failure to fade out support can have implications for the independence of employees, their social integration, and the cost-effectiveness of the service.

Parsons, Reid, Green and Browning (1999) describe a systematic programme to **reduce** job coach assistance for three adults with multiple severe disabilities, who worked in a publishing company. These adults all had a combination of an intellectual, physical and communication disability. Each person had one-to-one help from a job coach. Data were gathered on both worker and job coach behaviour. Systematic reduction of assistance was based on analyses of the type and amount of job coach assistance provided to each worker on each task. These reductions were through a combination of instruction and/or environmental modifications.

The effects of these interventions were huge reductions in job coach assistance, particularly completing work for the employees, which was reduced to almost zero. The job coach ratio was reduced from 1:1 to 1:2. There was a slight decline in productivity, but employees' average rate of pay (based on productivity) remained consistent after the study.

Issues around the reduction of paid support have also been considered in the light of using or transferring support provision to other people, an area called "natural supports".

"Natural supports" in the workplace

The provision of "natural supports" at work is a continuing focus in research on work for adults with an intellectual disability. A review of co-worker involvement in supported employment was published as early as 1988 (Rusch and Minch 1988). The provision of on-going support in the job site is the unique feature of supported employment which distinguishes it from other vocational services, **and** makes real work available to adults with a severe intellectual disability. What **are** "natural supports?"

Wehman and Bricout (1999) in a critical review of the concept of natural supports, note the lack of consensus on two issues: how are 'natural supports' different from other workplace supports? and, what is the role of the job coach in integration, compared to co-workers, supervisors, and employers? For some researchers and providers, the critical issue revolves around paid versus unpaid supports. Two examples of differing definitions of natural supports found in the literature reviewed by Wehman and Bricout are:

> *an individual's network of family and friends, and an employee's employers and co-workers on the job" (Hagner et al cited in Wehman and Bricout 1999).*
>
> *Natural supports refers to the utilization of co-workers from the onset of placement to train and support workers with disabilities throughout their employment period… Supports and strategies that are inherent to a particular work environment such as co-workers, supervisors and managers… It may involve continuing skills training… advocacy… job modifications and adaptations (Lee et al, cited in Wehman and Bricout 1999).*

What are the most common features in research and discussion about natural supports? Wehman and Bricout draw the following conclusions:

- the co-worker is the most frequently mentioned person
- some authors see the role of the job coach as **facilitating** natural supports, while others view job coaches as totally outside of natural supports; some emphasise the decrease over time in the role of the job coach
- some authors include natural supports outside the workplace eg, families, friends, community workers
- most authors agree that the setting for natural supports is the workplace, although some include a network around the whole task of finding and keeping a job.

Before examining specific studies of "natural supports", it is helpful to consider research on co-workers' attitudes and behaviour. Even though they are the most frequently cited providers of natural supports in the workplace, there appears to be very little published research on their attitudes and perceptions.

Shafer, Rice, Metzler and Haring (1989) surveyed 212 co-workers who worked in proximity to workers with an intellectual disability. They found that those co-workers who actually identified workers as having an intellectual disability expressed more comfort and acceptance. They also gave higher social and vocational competence ratings for people with a severe intellectual disability. They found that the amount of contact and level of disability did not have a significant effect on co-workers' attitudes. Many of these

co-workers were not even aware that they worked with an individual who had an intellectual disability.

Yan, Mank, Sandow, Rhodes and Olson (1993) examined co-workers' perceptions of an employee with a severe intellectual disability. They found that this employee was perceived by her co-workers as socially involved at levels comparable to others in this work setting. Actual observations confirmed that her average number of reciprocal interactions were very close to that of her co-workers.

Wehman and Bricout (1999) provide a critical review of research on natural supports published before 1998. This review will therefore summarise their findings and add available research published after 1998. Wehman and Bricout note that in the 15 studies reviewed by Test and Wood in 1996, less than 100 participants were involved in all these studies. They conclude that "research is needed to determine what strategies based on the concept of natural supports lead to improved consumer outcomes" (p 221).

While surveys of supported employment providers show the majority claim to emphasise the use of natural supports, the emphasis appears to be on using co-workers or supervisors for initial training, monitoring, and support. Natural supports are much less likely to be used in the initial stages of job development and placement.

Natural supports were not successful in high stress environments that were unsupportive to **all** workers, disabled and non-disabled. While supported employment providers believed that natural supports did contribute to success, they identified the following problems:

- some employers "resisted" assuming responsibility for training, supervision, and support of the disabled employee
- many co-workers did not have the skills to provide appropriate supports.

Wehman and Bricout conclude that it is not feasible or useful to try to separate the effects of job coach versus natural supports, as all supported employment programmes combine the two in varying ways. It appears that numerous factors influence outcomes for individual adults with an intellectual disability. Most adults with an intellectual disability will need support at different times in their jobs, but this will vary in terms of levels and intensity of supports (p 223). Finally, effective supports – whether "natural" or more unusual – must be available on a long-term basis. Wehman and Bricout summarise their review evidence by answering frequently asked questions about the use of natural supports in supported employment.

- Natural supports have **not** changed the concept of supported employment.
- Using workplace supports **can** facilitate consumer choice.
- Natural supports do **not** eliminate the need for job coaches.
- Consumer's needs for workplace supports differ widely.
- Consumers (ie, adults with an intellectual disability) **cannot** automatically access community and workplace supports on their own (Wehman and Bricout 1999: p 225).

Since this review of research, this area of research has continued to expand. Certo, Lee, Mautz, Markey, Toney, Toney and Smalley (1997) present a detailed case study of a

young woman (Lisa) with a moderate intellectual disability, and her life over a 12-month period. Natural support relationships were developed at work, at a local community college class, and at a local fitness centre. The process began at a person-centred planning meeting which included Lisa's own family and friends, as well as disability support staff. From this meeting a variety of detailed activities were undertaken, with a focus on preparing individuals at all sites to provide appropriate support. The job coach's role became to help Lisa **outside of** work to increase her independence at work, eg, learning the names of other staff, and helping her to advocate more for herself at work.

At the end of the year, Lisa took responsibility for initiating and organising her own person-centred planning meeting, and issuing 17 invitations to her greatly expanded social network. Two years later she was still working in the same job and had gained another part-time job as well. Her mother had learned the important lesson of "letting go". She commented:

> *I think that it's very important for me to stay out of Lisa's life at her work and to stay out of the other things that she's doing (p 40).*

Certo et al proposed some useful lessons from this case study:

- services need to be individualised and person-centred
- maximal use should be made of the natural supports in each setting, from the beginning of a placement or involvement
- simple techniques are effective in building support networks (eg, modelling interactions, "hanging-out" at social functions, redirecting questions and comments, building trust, reassuring people, encouraging formal and informal interactions, facilitation)
- making good friends is much more difficult than facilitating natural supports in the context of work.

While much of the emphasis on natural supports has been on its effect on social integration at work, there may also be economic benefits for adults with an intellectual disability. Mank, Cioffi and Yovanoff (1999) investigated the impact of natural supports (in the form of co-worker involvement) on social integration and wages earned. In this study, Mank et al were particularly interested in the type of training co-workers received. A multivariate analysis of co-variance was used to investigate the relationship between aspects of co-worker training and various employment outcomes. The results supported the value of co-worker training:

- in settings where co-workers received training on how to support adults with an intellectual disability, supported employees earned more money per month, and were more socially integrated in the workplace
- training for co-workers was also related to the "typicalness" of the supported employees' total work "package" (ie, wages, hours, benefits, work schedule)
- employees whose co-workers were trained in the immediate work area had significantly higher wages and greater social integration
- formal planned training was the only type of training to show these relationships; and training **before** the employee started work
- level of intellectual disability did not affect these findings.

Mank et al conclude that the results provide strong quantitative confirmation of the findings suggested by earlier qualitative studies (p 391). They identify five implications for supported employment providers:

- information and support should be provided to co-workers and supervisors in the worker's immediate work area
- information to co-workers should occur in planned meetings individually or in small groups
- information should be specific to the support needed by the employee with the disability (ie, **based** on the person, the job, and the company)
- co-worker involvement should be developed at the **beginning** of job placements (ie, begin early and be part of the whole supported employment process)
- general disability awareness training may be a useful strategy for promoting a general, positive attitude in the workplace to people with a disability
- more comprehensive co-worker training is associated with higher wages, better integration, and more typical employment for adults with an intellectual disability.

Mank, Cioffi and Yovanoff (2000) provided further research evidence on the relationships among direct job coach support, co-worker training, and wage and integration outcomes. Concern had been raised that a high level of job coach support could lead to less typicalness in the job, poorer integration at work, and lower wages. This study involved gathering detailed data on a total of 538 employees with disabilities. The data included information on: demographic variables, co-worker training, levels of direct support, levels of indirect support, and different types of employment outcomes eg, wages, social integration. Level of disability was used as a covariate. The results of the complex analyses were:

- employees receiving greater amounts of direct support (from a job coach) were **less** likely to be in settings in which co-worker training was provided
- direct support was positively associated with indirect support
- the effects of direct support were negative when there was no co-worker training, and vice versa
- worksite integration was negatively associated with direct support and positively associated with co-worker training
- direct support had a negative association with wages, whereas co-worker training had a positive association
- the positive effect of co-worker training was particularly marked for those employees who had four or more hours of direct support (p 510-4).

In conclusion, this study showed that even if there is a high level of job coach support, as long as there is also co-worker training and involvement, positive outcomes are likely for adults with an intellectual disability in supported work. Mank et al conclude that "it appears that, in most cases, the presence of co-worker training moderates the negative effects of direct support" (p 515). The implications are that:

> *Supported employment will benefit from developing better methods of involving co-workers in all instances of supported employment because of its clear relation to outcomes (p 515).*

Co-worker training was also evaluated in a study by Farris and Stancliffe (2001). Staff attended a two-day co-worker training course, in order to learn how to provide direct job training and support to workers with an intellectual disability in 11 KFC restaurants. Compared to workers who received support only from job coaches, those who received co-worker support:

- had equally positive employment outcomes
- received much less support from job coaches
- experienced high levels of involvement with co-workers.

Farris and Stancliffe point out the possible implications for the costs of supported employment, with a saving in paid training and support time. In fact, this could be seen as cost-shifting to the employer, but most employers bear the training costs for other employees.

Finally, Ohtake and Chadsey (2001) provide a detailed analysis of the different roles and combinations of roles that co-workers and job coaches can play in supporting workers with an intellectual disability. They outline a continuum of six possible strategies and roles for job coaches and co-workers:

- autonomous support by co-workers
- suggested support from job coaches to co-workers
- managed support of co-workers by job coaches
- instructional support by co-workers
- direct training by job coaches with consultation from co-workers
- direct training by job coaches (p 89).

Ohtake and Chadsey suggest that the critical issue is matching the right amount and type of support to the needs of each individual worker. Too much or too little support results in problems for the worker. The issues that need careful consideration are:

- the specific needs of the supported employee for support
- the needs and preferences of co-workers
- the overall culture of the work setting
- the issue of who decides about the selection of a support strategy.

Different strategies are likely to be needed at different times and to meet changing needs. Furthermore, the issue of support should not be obscured by the primary need to make a good job match. Ohtake and Chadsey conclude that "the most pressing research need is deciding which support strategy is the best match for a particular work situation" (p 94). The issue of support is also a factor in the continuing attention in the research literature to the costs of supported employment, particularly given its emphasis on individualised, long-term support.

Cost-benefit analyses of supported employment

Supported employment has often been perceived by funders as an expensive option because of its focus on supporting individual workers on a long-term basis. The early

days of supported employment in the US therefore resulted in a number of cost-benefit analyses of early programmes, for example, Rhodes, Ramsing and Hill (1987). Hill and Wehman (1983) reported on an analysis of actual costs and tax monies saved over a four year period in a specific job training and placement programme. This study did not focus on wages earned by the adults with an intellectual disability. This analysis found that, after four years, the cumulated public savings totalled US$620,576, while total expenditure was $530,300. Thus the total benefit to the taxpayer was US$90,376. Hill and Wehman also report that the total earnings by the 90 adults with moderate and severe intellectual disabilities over the four years was $506,734. These significant cost-benefits were evidenced after two to three years' operation of the programme. Thus there was a progressively increasing financial benefit to the taxpayer, quite apart from the benefits to the workers themselves. It is relevant to note, however, that this particular programme was a federally funded demonstration project based at a university, which is likely to have more expertise and resources than other settings.

Hill and Wehman extended this initial study to a longitudinal analysis of eight years of the programme (Hill, Wehman, Kregel, Banks and Metzler 1987). This extended analysis showed a final financial benefit to the taxpayer of US$1,057,000. More than half of this was a direct benefit of placing adults with moderate and severe intellectual disabilities in supported employment. All of these adults also benefited financially.

Comparisons of cost-benefit studies are difficult due to the methodological problems in this area of research. Rhodes et al (1987) identify four recurring issues:

- determining adequate comparison groups
- reducing all effects to a single benefit-cost ratio
- valuing benefits that cannot readily be converted to a dollar value
- obtaining adequate data systems needed to do comprehensive benefit-costs analyses (p 178).

Rhodes et al provide an extensive list of 32 cost-benefit effects (p 180) that could be included in evaluations of employment services. They suggest that the set of measurements for economic analyses should include, at the very least:

- a net gain to consumers, as well as wages paid
- a representation of how many public dollars are required from each service option to generate the major service outcomes
- a determination of whether the service is economically viable for providers and employers
- an establishment of the effect of the program on government (Rhodes et al 1987: p 179).

Later studies compared the cost-benefits of supported employment with day activity centres and sheltered workshops. For example, Noble and Conley (1987) concluded, from an analysis of data on 12 programmes, that **all** forms of employment were more productive and less costly than adult day care. Earnings were clearly higher for employment in regular job settings. However, one of the major reasons for this was in the differing hours worked, rather than higher hourly earnings. Also, client earnings were **not** related to severity of disability. They note the limitations of the data then available to undertake full cost-benefit studies, and the problems of comparability of the data.

An early Australian study also confirmed the cost-benefits of supported employment. Tuckerman and Bigsworth (1988) reported on a cost-analysis of a supported employment project, undertaken by Coopers and Lybrand W.D. Scott. The cost study provided a forward projection of costs per person, a comparison with the costs of sheltered workshops, and an estimate of the size of the programme necessary for the government to "break even". For the purpose of this review, the latter two results are of interest.

The study found that the "net present value of the stream of net total government expenditure per (supported employment) client was significantly less than that for workshop employees" (p 15). Secondly, the study estimated that "break-even" would be reached two years after the programme's commencement. These results were based on the high job retention results in the programme to that date. It should be noted that these estimates relied on forward projection, and that this supported employment programme served adults with mild and moderate intellectual disabilities.

In 1990, Tines, Rusch, McCaughrin and Conley published the results of a cost-benefit analysis of 25 supported employment programmes in Illinois, based on 1987 data, the first year of the programme. Previous studies had suggested that costs were greater than benefits during the first years but costs decreased and benefits increased over time.

Tines et al presented cost-benefit analyses from the perspectives of three stakeholders: society, taxpayers, and supported employees, as follows:

- **society:** the benefits were increased earnings and decreased expenditure by alternative programmes, whereas the costs were the actual costs of the supported employment programmes
- **taxpayers:** the benefits were taxes paid by the supported employees, reduced public benefits paid to these employees, and reduced operational expenditures by alternative programmes; the costs were the actual costs of the supported employment programmes and the tax credits for targeted jobs
- **supported employees:** the benefits were their net increase in income.

The results were as follows:

- **society:** total societal benefit of US$1.254,487 and the total societal costs were US$1,668,752, giving a **total net cost of $414,265** ie, for every dollar spent, the return to society was 75 cents
- **taxpayers:** total benefits were US$1,099,670, and costs were US$1,668,752, giving a **total net cost of $569,082** ie, for every dollar spent, the taxpayer received 66 cents
- **supported employees:** the net increase in their earnings was US$154,817 ie, their personal disposable income increased by 37 percent in the first year of the programme.

Tines et al point out that the reasonable expectation was that, over time, benefits would rise and surpass costs which would fall (p 52), based on previous research. Because job tenure is essential for the increase in benefits, long-term support provided to employees on the job becomes critical.

A nationwide study by Sale, Revell, West and Kregel (1992) provided an analysis of expenditure by US states on supported employment programmes for the fiscal year 1990. They found an increase of 19 percent from 1989 to 1990. There was also an increasing use of general state funding over special grant funding, through the Rehabilitation Act Amendments of 1986, ie, supported employment had become more integrated into the states' human services system (p 244). Sale et al also found enormous variations between states on their expenditure on supported employment, even when standardised in relation to states' wealth and population.

McCaughrin, Ellis, Rusch and Heal (1993) extended the findings of the Tines et al study in Illinois to cover five years, although the study only included two agencies, which provided both sheltered and supported employment, and 20 clients. In addition, quality of life benefits to supported employees were included as an assessment of cost-effectiveness. The study compared sheltered and supported employment. Comparison samples were randomly selected and then matched pairs were established in the contrasting group.

By the end of year five, supported employment showed benefits outweighing costs for society, the taxpayer, and the employee. In terms of cost-effectiveness, quality-of-life gains were greater for supported employees, and also were achieved at a lower cost. These gains were most marked for adults with a moderate or severe intellectual disability. The one finding of concern is that supported employees experienced greater loneliness on the job than did those who remained in the sheltered workshop (p 47).

Cost-benefits may also vary depending on the personal characteristics of supported employees. Cimera (1998) examined issues of cost-efficiency and their relationship to characteristics such as severity of disability, age, gender, and ethnicity. Cimera noted that previous studies examining severity of disability had resulted in conflicting findings (p 281). Cimera's study looked at two time periods (1990 and 1994), and also undertook a projected lifelong analysis.

Cimera's random, stratified sample of 166 supported employees was drawn from 2,397 individuals with a disability in supported employment in Illinois. Six independent variables were used: IQ; mild intellectual disability vs. moderate/severe/profound intellectual disability; multiple disability; gender; ethnicity; and age. The dependent variables were cost-benefit ratios, analysed from three perspectives: society, the taxpayer, and the supported employee. Each personal characteristic was correlated with the nine different cost ratios.

The findings were as follows:

- IQ was positively related to cost-benefit from the employees' perspective, but not from societal or taxpayers' perspectives; the same results were found with severity of disability
- regardless of severity of intellectual disability, it was cost-efficient to provide supported employment to **all** individuals, for all time periods
- it was also cost-efficient to serve individuals with multiple disabilities
- in terms of gender, differences were only found at one time period in favour of males; it was cost-efficient to serve both genders at all time periods

- ethnicity was correlated with cost-efficiency in some areas, with African Americans showing greater cost-benefits from supported employment
- age was not correlated with cost-efficiency at any time period.

Cimera (1988) concludes that:

> *supported employment programs are a good investment for workers, taxpayers, and society in general. Even more important, results showed that regardless of the severity or number of disabilities, supported employment is cost-efficient for all individuals (p 290).*

Despite the establishment of its cost-efficiency and cost-effectiveness, supported employment can improve its outcomes. Revell, Kregel and Wehman (2000) present preliminary findings from research on the key characteristics of successful funding designs for supported employment programmes. Their recommendations are:

- balance the interests of key stakeholders through collaboration
- ensure that funding levels are workable for providers of service
- tie payments to achievement of valued performance measures
- emphasise individualisation, flexibility, and choice
- avoid creating disincentives to serving people with the most significant disabilities.

Supported employment services have been present in New Zealand for at least a decade, but there has been little evaluation of their cost-efficiency or cost-effectiveness. Robinson and Bishop (2000) published cost-benefit results from one supported employment service which provided individual support services for 128 people with different disabilities, over a six year period. Among these 128 clients, 56 had an intellectual disability, and 10 had multiple disabilities. Over 66 percent of clients had been maintained in jobs for longer than one year.

Robinson and Bishop included an additional assumption in their cost-benefit analysis – the percentage of non-disabled workers displaced by supported workers. They calculated an overall displacement rate of 60 percent. At this displacement rate there was a net benefit to the taxpayer and to society. They conclude that even with a displacement rate of 85 percent, supported employment services are beneficial from taxpayers' and society's point of view (p 98). When considerations of outcomes are also factored in, there are also a number of non-financial benefits which contribute to the broader goal of cost-**effectiveness.**

Robinson and Bishop note two earlier New Zealand studies. One by ASENZ (1997) concluded that favourable cost-benefit ratios for individual supported employment programmes emerged after 3.5 years of service provision (p 90). The second report on the Government's Mainstream programme recommended two years' provision of funding and support per person.

Summary

Supported employment models and practices have dominated the research literature on work for adults with an intellectual disability for the past twelve years. Practices have changed from group models to a preponderance of support for individuals on-the-job.

The growth of supported employment has implications for other services, particularly high school and transition programmes.

Evaluations of supported employment programmes have consistently shown a range of positive outcomes in income, independence, and self-esteem for adults with an intellectual disability. Comparisons with sheltered employment typically favour supported employment services. Nevertheless, the majority of adults with an intellectual disability in Western countries do not have access to supported employment services, but attend sheltered workshops or day services.

The provision of extended support on-the-job is one of the unique features of supported employment, and is particularly necessary for adults with more severe disabilities. It is needed for a variety of reasons, including job training, social skills development, training of co-workers, advocacy, and career development.

While high job turnover may be found for supported employees, this is also characteristic for other workers in the entry-level jobs in which adults with an intellectual disability often work. However, research has described strategies to minimise job loss, and the negative experiences that may accompany that.

Funding for on-going services has been a challenge for many agencies providing supported employment services.

Supported employment calls for a range of expertise and skills, not typically required in traditional services. The role of "job coach" usually requires a range of skills and knowledge, beginning with marketing and job development. Research suggests that many staff in these roles may not have the necessary qualifications and skills required for their positions, which tend to be poorly paid. Staff training in supported employment may often be minimal, but research suggests that more expert "on-site" technical consultancy and support is the preferred training option.

Difficulties in service quality may also be due to organisational performance rather than staff training needs, particularly given the difficulties in service change and development.

Employers value the range of activities and support provided by job coaches, particularly those involving regular communication and monitoring the employee's performance.

The scope of staff roles in supported employment has widened to include job developer and ensuring or providing personal assistance to adults with additional physical disabilities.

A final challenge for job coaches in the process of providing individualised support is the "fading-out" or reduction of that support, a task that may be personally stressful for the job coach.

The issue of "natural supports" in the workplace is a continuing focus of research. "Natural supports" usually refers to the supervisors and co-workers of the supported employee. Facilitating natural supports is often seen as an important role of the job coach.

Studies of co-workers' attitudes have shown that, on the whole, co-workers have positive attitudes towards the employment of adults with an intellectual disability, particularly if this is within their personal experience.

Research on the use of natural supports suggests the need for skilful facilitation of such supports, particularly in the areas of training, supervision, and social inclusion. Furthermore, structured natural supports are likely to be needed for some employees on a long-term basis. Some research suggests that the inclusion of natural supports is necessary very early on in the process of supported employment, particularly the active inclusion of the person's existing support networks.

Natural supports can have both social and economic benefits for the supported employee implying the need for job coaches to plan their inclusion early and systematically. Research also shows some negative outcomes of a high amount of direct job-coach support without co-worker training and involvement. Co-worker training has also shown positive outcomes for supported employees.

The issue of promoting natural supports has been part of concerns about the financial viability and cost-effectiveness of supported employment programmes.

Research on the cost-benefits of vocational services for adults with an intellectual disability varies in methodology and sampling, and provides conflicting results. However, in general, the cost-benefits of supported employment are progressively greater, over time, for employees, society, and the taxpayer, compared to day services and sheltered workshops. These results do rely on the provision of quality supported employment services, as job retention is important.

When cost-effectiveness is studied (ie, including the non-fiscal benefits to adults with an intellectual disability), the value of supported employment is even more obvious.

The cost-benefits of supported employment are found whatever the degree of disability or characteristics of the adult with an intellectual disability. However, there is a relationship between disability and level of income achieved.

New Zealand research has supported the findings of overseas cost-benefit studies.

CHAPTER SEVEN

SUPPORT AND INTERVENTION STRATEGIES AT WORK

Supported employment for people with a severe disability?

Supported employment was initially developed as a strategy to enable adults with a severe disability to work for pay in integrated settings. However, as previously noted, the majority of people served in most programmes have had a mild or moderate disability. Even when people with a severe disability were being supported in paid jobs, research has been critical of the quality of outcomes for some of these workers.

Wehman, Hill, Wood and Parent (1987) studied the emplo yment experiences of 21 adults with a severe intellectual disability (defined as an IQ below 40) over an eight-year period, from 1978 to 1986. This competitive employment programme was based at a major university in the US. All of the adults worked in entry-level service positions, such as dishwashing. None of them had ever worked before. Most of them were rated by their supervisors as adequate or better after a few months of work (p 13). Their cumulative earnings were US$231,976. Thus the data showed that these workers could succeed in competitive employment, given appropriate staff support at the job site.

However, Wehman et al also note a less positive side to this picture. Many of the workers could not get fulltime work, and the jobs were all entry-level service positions. Significant hours of support were necessary and would continue to be so. The job retention rate of 55 to 60 percent was less than optimal. These adults did not have serious mobility or sensory difficulties, which many adults with a severe intellectual disability have. One of their major problems was limited social skills and problems relating to other workers.

A later study by Mank, Cioffi and Yovanoff (1998) reiterates some of the issues raised by Wehman et al. They noted that, in 1995, fewer than 7 percent of adults in supported employment had a severe or profound intellectual disability (p 206). Mank et al studied the employment features and outcomes of 462 people with a severe disability in supported employment, in eight states, compared to people with a less severe disability.

Complex univariate and multivariate analyses were undertaken on a large data set of demographic and job information on each individual. The analyses showed that adults with a severe disability:

- earned significantly less money, had worked fewer months in their current job, and had fewer interactions at work (p 208)
- were perceived as having lower work rates, poorer work quality, and less positive relationships with co-workers
- experienced fewer typical features of employment than those with milder disabilities
- were more likely to have challenging behaviours and need help with personal care
- received a greater number of hours of direct job support and their co-workers and supervisors received more indirect support

Mank et al also looked for individual exceptions to these trends, ie, those adults with a severe disability with high outcomes, and those adults with a milder disability with poor outcomes. They found that the "high achievers" were more likely to:

- be perceived as doing their job in accordance with work site practices and customs
- have more typical work rates and work quality
- have good co-worker relationships
- have had their co-workers receive training from supported employment staff
- be receiving **less** than weekly support from supported employment staff
- have co-workers who received **less** support from supported employment staff.

Mank et al also compared workers with one or more "challenging behaviours" with other workers. Those with these behaviours had less positive employment characteristics and outcomes, and required more support hours. When the "high achievers" within this group were examined, similar findings to those "high achievers" with a severe disability emerged.

The three important findings from this study, as discussed by Mank et al are:

- high quality outcomes are possible for at least some adults with a more severe intellectual disability
- training of co-workers is related to better outcomes for adults with a more severe disability
- the patterns of hours of support for those with a more severe disability with higher outcomes was surprising. Possible explanations are: better "job matching"; co-workers with training are more likely to provide the needed support. More research is clearly needed on the role of co-workers and types of support needed.

While they acknowledge the generally lower outcomes for adults with a severe disability, found in this study, they conclude:

> *As the exceptions show, it is once again a matter of understanding support strategies that will improve community outcomes rather than assuming the label of severe disability is the reason for lesser community outcomes (p 216).*

How do other people perceive employment for adults with a severe intellectual disability? Black and Meyer (1992) asked respondents to rate videotaped samples of employment training of four adults with a mild to profound intellectual disability. The 188 respondents came from six groups: future teachers, government policy makers, rehabilitation counsellors, parents, business managers and supervisors, and potential co-workers.

The videotapes were made during actual community-based job training. One adult had a mild disability, while the other three had a profound intellectual disability and other multiple disabilities.

The analyses of the ratings of the videotapes showed the many dimensions in judgements of the social validity of supported employment training. Both the level of disability of the worker **and** the group identity of the respondents affected their judgements. Higher social value was placed on the training as the level of disability **de**creased. However, training was still valued even for the adult with profound, multiple disabilities who required

physical assistance to perform a work task. Even members of the business community made positive social judgements about integrated job training for people with a severe intellectual disability.

Ratings by future teachers were significantly more positive than those of potential co-workers and business managers. Black and Meyer note that the generally positive findings of this study may not be reflected in actual hiring practices or interactions in the workplace, but this study does suggest that negative attitudes may not be the major barriers to more work opportunities for adults with a severe intellectual disability.

The limited work options for this group have also been the focus of research. Sowers, Cotton and Malloy (1994) note that the vast majority are cleaning jobs which are low-paid, low-status, and physically demanding, all characteristics which contribute to low job satisfaction and poor job retention.

Sowers et al argue that greater emphasis needs to be placed on the **quality** of the job and job satisfaction, not just on "any job". This re-emphasis would result in more time and effort going into career planning and development. They suggest four strategies that need to be used:

- start with the person's special talents and interests
- explore different job and career areas
- provide the person with the opportunity to access typical education and training opportunities
- develop access to job opportunities in a wide array of career areas (p 57-8).

The apparently limited focus in job choices for people with a severe disability cannot be justified by their significant learning difficulties, as a large body of research on behaviourally-based training strategies has demonstrated that people who have a severe intellectual disability **can** learn. For example, Test, Grossi and Keul (1988) provided evidence of success in teaching a young woman with a moderate/severe intellectual disability to perform a complex set of janitorial skills. Her performance was also maintained at 100 percent accuracy over a 10-week period after training. Independent ratings by her job supervisor confirmed the continuing high quality of her work.

Simmons and Flexer (1992) also demonstrated that severity of intellectual disability does not prevent successful learning of job tasks. They compared the learning of two adults on the same janitorial tasks, using the same trainer and teaching methods. One adult had a moderate intellectual disability and the other had a severe intellectual disability. Both adults were in sheltered workshops and neither had been expected to be able to achieve the level of work needed in supported employment. Despite these low expectations, both adults learned to perform the tasks equally well, but it took longer to train the adult with the more severe disability. There were also differences in the number of pre-existing skills, with the less disabled woman having more of the skills required before the training even started. Once each person had mastered a skill, however, both showed generalisation of that skill to other parts of the job. Simmons and Flexer concluded that "people with more severe disabilities do need more assistance and support in learning due in part to their lower initial performance" (p 269). They also note that expertise in systematic training strategies is also needed to teach people with a more severe intellectual disability. As noted in a previous section, people working as job coaches or trainers do not

necessarily have the qualifications or skills necessary to devise and implement systematic, research-based training.

If ability to learn is not the real barrier to the inclusion of adults with a severe intellectual disability in supported employment, does severe problem behaviour pose the major challenge? There is some evidence that the technology exists to overcome this significant problem. Kemp and Carr (1995) provide evidence of successful interventions with three adults with an intellectual disability whose severe problem behaviours had resulted in removal from a supported employment programme and frequent removal from community settings. All three adults had diagnoses of autism and a severe intellectual disability. The work settings were greenhouses in community settings which also served walk-in customers.

Detailed assessments and observations preceded the interventions. Systematic teaching strategies were used to teach the work tasks. Work training sessions were initially very short to avoid protracted problem behaviour which would have affected the willingness of the employer to continue. Functional analyses were undertaken during the baseline sessions. These detailed analyses were then used to develop specific intervention procedures for each adult. The interventions involved the following five basic components:

- building rapport
- offering choices
- embedding demands
- functional communication training
- building tolerance for delay of reinforcement (p 235).

The interventions were introduced in a multiple baseline experimental design across the three workers. The job coach also trained the other employees in the intervention strategies. The employers completed a questionnaire to assess their perceptions of the outcomes of the intervention.

The interventions and training strategies were very successful and also evaluated as such by the employers and by co-workers. All three adults with a severe disability learned to complete a range of different greenhouse tasks without showing any significant problem behaviours following the multi-component interventions. The total period of training necessary for each employee was only 2 1/2 to 3 hours. By the end of the study, the three employees could work for four hours at a time. Each of them subsequently obtained other community jobs. This study demonstrated that employees with problem behaviours can receive intervention on the job, **and** they can also acquire jobs without the need to intervene on problem behaviour **first.** The training and intervention can occur simultaneously (p 246).

The value of a multi-component approach to workers with both an intellectual disability and challenging behaviours is also supported by Stevens and Martin (1999). They cite research by Hughes and Rusch (1996) who found that adults with an intellectual disability **and** challenging behaviours have the highest school dropout rate **and** the highest unemployment rate of all disability groups. They are also less likely to be involved in community activities (p 22). Martin and his co-researchers have applied the intervention strategies used by Kemp and Carr (1995) in work environments that require more social

interactions and greater unpredictability. Based on their work and previous empirical research Stevens and Martin present a useful model for supporting adults with challenging behaviours in community-based employment settings.

Supported employment has also demonstrated positive outcomes for adults with autism and Asperger syndrome. For example, Mawhood and Howlin (1999) describe the outcomes of a two year supported employment programme in London. A group of adults outside London provided a comparison group. There were significantly more positive outcomes for the adults in the supported employment programme, including:

- more in paid work (19 vs. 5); over 80 percent of the jobs were in administration or computing
- higher job levels
- in work for a greater percentage of the time
- significantly higher wages.

The adults in this study did not have a significant intellectual disability or any other psychiatric or physical problems. During the first two to four weeks of the job, the support worker provided fulltime support but this reduced until the end of the fourth month when only occasional support occurred. None of the supported workers were required to leave the job due to behavioural or other difficulties. The cost-benefit analysis undertaken in this study highlighted the significant costs incurred in the job finding and preparation phase, which was an essential part of the success of the project. These costs exceeded the costs of the actual support provided on the job.

Both employers and clients expressed satisfaction with the supported employment project. Some managers also commented on the personal growth and understanding, and communication skills they had developed through having employees with autism/Asperger syndrome. Clients also commented on their own personal development and development of better coping strategies and independence.

Mawhood and Howlin concluded that:

> *The key factors in ensuring a successful placement seem to be that clients and jobs are carefully matched; that support workers have a good understanding of the needs of people with autism or Asperger syndrome; and that they are able to advise and educate employers and supervisors (p 251).*

A later report follows on from the research by Howlin and Mahood. Nesbit (2000) analysed the factors that affect employment for adults with Asperger syndrome. She cites research by Goode et al (1994) which found that despite their potential for work, few adults with Asperger syndrome had regular jobs, even when they had formal qualifications. This loss of work or inability to find work also frequently led to low self-esteem and depression.

Nesbit compared organisations that were currently employing a worker with Asperger syndrome with organisations that did not. Questionnaires were developed from a focus group discussion and a pilot study, and then sent to 181 organisations, of whom 69 responded.

Organisations using the supported employment project rated five items as significantly more important than comparison organisations. All of these items related to understanding or awareness of Asperger syndrome, or awareness of the services offered by the supported employment project. In contrast, comparison organisations rated seven items as more important. These items related to the ability of the individual to do the job, to behave appropriately, and to interact with others.

The provision of relevant information was important to **all** organisations, but those organisations using supported employment were more open to information, and more willing to adapt and provide support. Business size and type did not affect these results.

A further group of adults often seen as ineligible for work are those with physical and multiple disabilities. Inge, Strobel, Wehman, Todd and Tangett (1999) provide evidence on a supported employment programme specifically designed to serve adults with major physical disabilities. They note some of the specific barriers and issues facing this group:

- physical capacity
- health issues
- mobility and transportation
- financial disincentives
- assistive technology needs.

In the particular programme described, the majority of people involved had never worked or had not worked for a long time. Over time, 21 adults with major physical disabilities were placed in employment, and outcomes evaluated. The majority of this group had either cerebral palsy (43%) or spinal cord injuries (38%). All of these adults required personal assistance (attendant care) services, and the majority also required personal assistance in the workplace. All of them also needed specialised transportation services. Many had significant communication difficulties and chronic health problems.

The six members of the project team included a range of specialist qualifications and skills, and the team also had access to a rehabilitation engineer. Each person's needs were assessed within a "real-life" setting related to the person's employment goals – not in a clinical setting. A person-centred approach to planning for work was followed, which involved each person's own network of family, friends, and support staff. Detailed informal assessments were undertaken of the person's functional capacity, personal needs and interests, and perceived barriers to employment. A detailed process of individual job development was then undertaken, with a focus on job restructuring to create appropriate job opportunities. This process took, on average, 12.4 weeks in large businesses, and 3.29 weeks in small businesses.

All of the participants also received extended job-training and support, typical of a supported employment model. Most of the assistive technology required were "low" technology, and the average cost of accommodations was US$112.35.

These authors concluded that this programme showed that people with major physical disabilities can benefit from supported employment. This finding is relevant to this review because of the frequency of physical disabilities among adults with an intellectual disability. They identified the major challenges the project faced as being:

- the development and use of effective marketing and job development practices
- the development and use of functional assessment procedures
- the use of effective technology supports
- the use of an effective media campaign to counter negative attitudes
- the development of long term and responsive funding (Inge et al 1999: p 147).

One of the difficulties with supporting people with multiple disabilities which include communication difficulties is assessing their work preferences. Parsons, Reid and Green (2001) evaluated the use of an observational assessment of three adults with multiple severe disabilities while they worked on different tasks. These observations identified distinct affective indicators of these adults' likes and dislikes, providing an effective way of assessing work preferences in people who may not be able to communicate them.

Another study by this research group (Parsons, Reid and Green 1998) described a procedure to identify work preferences for an adult with multiple severe disabilities and deaf-blindness. These pre-work assessments were predictive of later preferences for daily tasks in a supported employment position.

Evidence also exists regarding strategies to promote social inclusion at work for people with deaf-blindness and other multiple disabilities. Goetz, Lee, Johnston and Gaylord-Ross (1991) present four case-examples to illustrate specific strategies, including:

- ***heterogeneous group placements,*** in which a small group of adults with different levels and types of disability is dispersed within one work site, an unusual model of supported employment, but, it is argued, one which can be more cost-effective when one individual requires a high level of support
- ***job restructuring***
- ***volunteerism,*** in which the job is freely chosen **and** is one that has previously been held by a volunteer
- ***natural supports***
- ***facilitating social and communication interactions.***

There is thus evidence to support the claim that people with a variety of severe and multiple disabilities **can** be supported to work successfully. However, the provision of effective support is likely to require a range of skills and expertise. Research has also focussed on strategies to address difficulties in work performance and social behaviours at work.

Improving work productivity

One of the most basic requirements of all employers is that employees meet an acceptable level of productivity. Common assumptions are that adults with an intellectual disability will not be able to meet the standards of productivity expected of other employees, or that the training or support needed will be excessive. In response to such assumptions, a body of research has focussed on ways to improve the productivity of employees with an intellectual disability. Researchers have approached this from two perspectives: changing the work environment or improving the worker's skills or capacity.

Belfiore, Lim and Browden (1994) applied the principles of motion economy to examine the design of tasks and work procedures in two related studies of workers with an intellectual disability. The measures of work efficiency were rate of productivity (Study 1) and total task duration (Study 2).

In the first study, seven workers with a moderate intellectual disability were involved in a packaging assembly task. A new task design which used fewer movements was designed. This redesign involved environmental modifications to the work station and designing new materials. These changes resulted in improved production rates for all workers, with an average increase of 77 percent.

The second study involved a vacuuming task and three workers with a moderate to severe intellectual disability. The redesign of this task focussed on the gross motor movements required to complete the job. After training on this new method, all three workers showed a decrease in the time needed to complete the task. There was also improvements in the size of the area actually vacuumed, ie, not left uncleaned.

These studies illustrate the importance of evaluating task design as a critical factor in the productivity of all workers, including those with an intellectual disability.

There are general factors apart from task design and intellectual disability which can affect work productivity. Research has also considered other disadvantages that adults with an intellectual disability may bring to their work. A body of health research, for example, has documented the poor strength and fitness levels characteristic of many adults with an intellectual disability. Also, there is increasing attention to employee health and fitness among an increasing number of employers. Zetts, Horvat and Langone (1995) studied the effect of a progressive resistance exercise programme on the work productivity of six young adults with a moderate to severe intellectual disability. The programme resulted in increased strength for all participants in all muscle groups, and increased productivity on all work tasks, which all required physical activity.

A major concern among employers and funders of services such as supported employment has been the possible need for significant and long-term support to monitor and maintain work productivity in employees with an intellectual disability. A continuing focus in research, therefore, has been on identifying effective self-management procedures which can increase and maintain work productivity.

Lagomarcino and Rusch (1989) provide an example of research involving a young man with a profound intellectual disability. Using detailed single-case study experimental design, these researchers identified the type of carefully designed teaching procedures by which an adult with a profound intellectual disability can successfully learn to work more independently and to improve his productivity by monitoring and rewarding his own behaviour.

Moore, Agran and Fodor-Davis (1989) confirm the viability of teaching adults with a severe intellectual disability to improve and maintain their work productivity through self-management techniques. All four adults in this study had a severe intellectual disability. The multi-component training package included self-instruction, goal setting, and self-reinforcement. The programme resulted in improved productivity for all workers for at least three months.

A New Zealand study (Straight and Blampied 1998) examined the impact of self-management on the productivity of 11 adults with an intellectual disability in a special work cooperative. Eight workers showed increases in productivity when self-monitoring was combined with extrinsic rewards, but these increases were not maintained when these rewards were not provided. The researchers discuss a number of possible contributions to this result, including the lack of workers' involvement in setting their own production targets and the lack of choice of "rewards" to match individual preferences.

The studies outlined here have a number of limitations, in terms of generalisation to other work:

- the settings are all in sheltered rather than real employment
- the work task in most studies involves assembly or packaging
- the training typically involves highly structured, controlling, "non-natural" techniques, which are not characteristic of real work settings
- the focus is on individual, competitive productivity and single-person tasks
- training is typically provided by researchers, not employers or co-workers.

Later studies of self-management have been undertaken in community employment settings. Grossi (1998) examined the use of a self-operated prompting system on the work performance of two adults with severe disabilities. Both adults were permanent, paid employees in community work settings, and needed to improve their work performance, or they were at risk of being fired. Both workers used a self-operated tape player with headphones, and self-selected music interspersed with audio prompts about working. The work performance of both adults increased significantly using this self-prompting system.

Another study by Grossi and Heward (1998) used a self-evaluation training package to improve the work productivity of four men with a mild intellectual disability in a community-based restaurant training programme. All four men learned to set a goal, monitor their productivity, and measure their performance against a competitive standard. Work productivity by all four men increased over baseline levels when they evaluated their own performance, increasing their rates while still maintaining quality. Each of the men obtained a competitive job at the end of their training.

Browder and Minarovic (2000) demonstrated that non-readers can be taught sight words which they then can use to self-initiate job tasks. This study was initiated by some adults with an intellectual disability who found picture schedules inappropriate to their age and work setting. The training package used in this study included (a) teaching job task sight words (b) training the workers to use these sight words to initiate work on the tasks, and (c) evaluation of the workers' use of the sight words. The study participants were three adults with a mild/moderate intellectual disability who were in competitive, supported jobs. None were able to read. After being trained to read the task words and use them to initiate tasks, follow a schedule of tasks, and check their work, all three adults showed significant improvements in their level of work and independence. These improvements were confirmed by employers' ratings.

Work productivity, however, is not the only issue in getting and keeping a job. Workers also need to have social skills which are appropriate to their work settings. A body of

research has examined the area of social skills at work, and the wider area of social integration at work, a very important outcome of successful work.

Improving work-related social skills

What sorts of social skills are related to work success for adults with an intellectual disability? A study of job terminations of adults with disabilities found that the majority were due to "social problems" (Hanley-Maxwell, Rusch, Chadsey-Rusch, and Renzaglia 1986). Chadsey-Rusch (1992) noted that two general classes of social behaviour are important at work: those related to the work task themselves, and those that occur apart from the actual work task. She defines social skills as:

> *goal-oriented, rule governed learned behaviours that are situation-specific and vary according to social context; they also involve both observable and non-observable cognitive and affective elements that assist in eliciting positive or neutral responses and avoiding negative responses from others (p 408).*

The most critical point in this definition is that social skills are **learned.** It logically follows that social skills can be taught to workers with an intellectual disability. While the complexity and variety of social skills and behaviour needs to be acknowledged (Chadsey-Rusch 1992), a body of research demonstrates the effectiveness of social skills training in promoting work success for adults with an intellectual disability. For example, Agran, Salzberg and Stowitschek (1987) evaluated the effect of a social skills training programme for five adults with moderate and severe intellectual disabilities in a sheltered work setting. This particular programme used self-instructions to promote maintenance and generalisation of the social skills. The social skills in this study were task-related: initiating contact with the supervisor when materials ran out, and initiations to request assistance. A complex, multiple baseline design was used to assess the effectiveness of the skills training package. Both observational data and employer ratings confirmed the effectiveness of the training.

Task-related and non-task related social skills are both important, but each appears to make a unique contribution to perceptions of overall work competence. Butterworth and Strauch (1994) examined the relationship between social competence and overall job success for adults with an intellectual disability. They note that interactions between workers and supervisors are primarily task-related, whereas interactions between co-workers are more likely to include a lot of non-task-related social interactions (p 119). In this study, 98 supervisors and 193 co-workers of 98 employees with an intellectual disability were asked to rate the employee's competence on 27 specific social skills, on overall competence as a worker, and on their own physical proximity to and relationship with the person.

The majority of ratings of overall competence and overall relationships were very positive. The measures of physical proximity and social relationships, however, suggested a relatively low level of social integration in the workplace.

An analysis of social skills clusters identified two factors, named "polite social interaction" and "task completion", which primarily relates to the **content** of the interaction. These two factors were also highly correlated, suggesting that respondents

themselves may not distinguish clearly between them. Butterworth and Strauch suggest that:

> *if the primary social context is completion of work, then effectiveness in that role may function as a prerequisite for development of a personal relationship… a worker who is not perceived as carrying a full share of the workload may not meet the minimum standards for the development of a friendship (p 128).*

The findings of this study suggest that job coaches will have to address **all** of the following: job training, task-related social skills, personal interaction skills, **and** the environmental factors that affect interaction, such as proximity to co-workers, interdependent tasks, how "breaks" are arranged.

For people with limited communication skills, adaptations and special interventions may be necessary. For example, Storey and Provost (1996) demonstrated how the use of communication books for two workers with severe disabilities increased their social interaction with other workers. These adults had minimal or no verbal skills. Data collection involved direct observations, rating scales, and a measure specifically developed to assess global integration at work. The multiple probe design across conditions showed significant increases in social interactions following training in the use of a communication book to initiate and participate in conversations during non-work times eg, breaks, lunch.

There is also evidence that adults with an intellectual disability can learn various social skills without direct teaching due to the range of models and "natural" reinforcers available in the typical work setting. Wacker, Berg, Visser, Egan et al (1986) maintained detailed data on the social interactions of two young adults with moderate and severe intellectual disabilities in a work setting over a three month period. They point out that "independence" at work involves far more than task performance. A case study design was used to provide descriptive information only on the occurrence of pre-identified "incidental" (ie, untaught) positive behaviours, that had not been previously observed by each worker. Both workers showed marked increases in the number of incidental behaviours, with increases in daily occurrences, cumulative increases of at least 22 new behaviours, and a positive ratio of positive versus missed or inappropriate behaviours. In addition therefore to an ability to learn new work related skills and social skills when taught, adults with an intellectual disability learn from their environment.

Riches (1995) identifies a trend towards more employment opportunities in the service and retail sectors, in which social interactions are more important. The research reported by Riches involved a cooperative social skills training programme between supported employment agencies and a College of Further Education in Australia. The programme evaluation included multiple data sources and methods. Most of the 16 students in the programme had previously been in sheltered employment. Follow up of student outcomes after the programme showed 50 percent were involved in employment or further education, even though local unemployment was 11 percent. It is not possible to identify which course components were most critical. However, general improvements in self-esteem and self-confidence, and improved work-related social skills, were noted by all stakeholders, including the students themselves.

Selecting the most appropriate social skills to teach or encourage and how to intervene are not decisions that should be left to job coaches alone. Baumgart and Askvig (1992) showed how useful it was to ask managers and other employees for suggestions on appropriate interventions. These researchers surveyed 280 employees and managers from 140 businesses with at least two entry-level positions, half of which had employed people with an intellectual disability. These staff were asked to respond to 14 hypothetical scenarios which depicted adults with an intellectual disability in the workplace, showing specific social skill problems. The social skills used were based on previous work by Baumgart and Anderson (1987):

- honesty
- following directions
- proper hygiene
- controlling anger
- asking for help/assistance
- showing interest/enthusiasm in job
- cooperating with co-workers
- maintaining appropriate dress
- accepting criticism
- accepting schedule changes
- refraining from personal business on the job
- calling in if sick or late
- being on time to work or from breaks
- interacting appropriately with customers (p 347).

Two experts rated each intervention suggestion as appropriate or not appropriate, with supporting justifications. Managers had a higher proportion of responses rated as appropriate than did the employees. The overall proportion of appropriate suggestions was 75 percent. The most frequent reason for a response being rated as inappropriate was that it did not teach or provide a **learning** opportunity for the skill that was needed. This study provides support for the increasing use of other employees as trainers and providers of support for workers with an intellectual disability.

Finally, Linneman and Chadsey-Rusch (1996) emphasise that simply focussing on changing the social behaviour of workers with an intellectual disability is a limited approach. Social **relationships** are a very important aspect of job satisfaction for most employees. Strategies are needed to change the work environment or the ways that social activities are arranged, as well as sometimes changing the behaviours of co-workers towards the employee with the disability. Linneman and Chadsey-Rusch are critical of previous research which fails to measure the desired outcomes of social skills training focussed on the worker with the disability. Facilitation of interactions may need to consider factors such as:

- proximity
- ordinary social activities available
- social opportunities
- the culture of the work setting
- cooperative tasks.

All of these factors can contribute to increased co-worker interactions with the employee with the disability, and can enhance the learning of social skills and social inclusion. The next section will consider studies which focus specifically on this issue of social inclusion or integration.

Social integration at work

One of the major rationales for involving adults with an intellectual disability in ordinary jobs is to avoid segregation and promote inclusion into the local community. Work has also been seen as an important site for developing friendships. The area of social integration at work has therefore been the focus of a large body of research. This review will present the findings of a recent research review and add some studies published since this 1998 review.

Social integration is defined in differing ways by various researchers but a common theme in these definitions is:

> *the notion of full participation in social interactions by those with disabilities to the same extent as it is experienced by people without disabilities who comprise the social ecology of an environment (Hughes, Kim and Hwang 1998: p 173).*

However, mere physical proximity to other people at work does not guarantee social interactions.

Hughes et al (1998) reviewed published descriptive studies involving direct observation of adults with an intellectual disability at work. The review covered research published from 1985 to 1995. The purpose of their critical review was:

- to identify measures used to assess social interactions of employees with and without disabilities
- to aggregate findings describing social interaction patterns in employment
- to compare findings to those of social skills interventions conducted in the workplace
- to critically evaluate the knowledge base of measures of social integration of employees with disabilities (p 174).

Twelve articles met the selection criteria for the review. This review concluded that, with regard to social interaction in employment:

- interaction was affected by the environmental context and the presence or absence of intellectual disability
- employees with an intellectual disability initiated more interactions with other disabled workers, whereas employees without a disability initiated more interactions with non-disabled co-workers
- employees without a disability engaged in more work-related interactions than did workers with an intellectual disability
- more social-related interactions occurred during breaks than during work, for all employees
- all employees interact more with their co-workers than with supervisors

- when a job coach was present, employees with an intellectual disability interacted less with non-disabled co-workers
- most interactions in which disabled employees were involved included greetings or receiving or requesting instruction
- non-disabled employees spent more time asking for information, joking, and teasing
- inappropriate interactions rarely occurred.

Hughes et al then compared these findings to 32 social skills intervention studies in work settings.

They found that the majority of social skills or behaviours which were targeted for intervention were job-related skills:

- requesting assistance
- complying with instruction
- responding to criticism
- inappropriate behaviours
- initiating and taking part in conversations (p 180).

Hughes et al concluded that many of the studies focussed on the same "employer-identified" social skills, and may not be valid measures of the social integration of employees with and without an intellectual disability. Co-workers may value different behaviours than employers. Co-workers' typical social behaviours were rather different to those targeted in the intervention research, suggesting a problem of social validity in much research.

A further conclusion from this research review is that measures of social interaction in one work setting may not be valid in a different work environment. The 12 studies took place in over 70 different work settings. Hughes et al point out that "expectations of social behaviour derived in one job setting should not be expected to be relevant in another setting" (p 182).

There were discrepant findings across studies which probably related to contextual or demographic variables which were not considered or analysed in most studies. Furthermore, many studies averaged findings across groups which may not be descriptive of the entire sample. There were also differences in observation methods across studies which would be expected to lead to variations in findings.

Hughes et al also conclude that few studies reported measures of social acceptance of quality of social interaction. These characteristics are likely to be crucial for the development of friendships.

Finally, the major targets of social interaction intervention have been in behaviours that are rarely seen in the descriptive studies of social interaction in **any** employees. On the opposite side, few interventions have focussed on frequently occurring behaviours that non-disabled employees display. Hughes et al conclude that

> *Intervention efforts should focus on promoting valued social behaviour among workers with disabilities and providing the supports needed to increase their social acceptance and full participation in their employment settings (p 184).*

More recent studies appear to be addressing the issue of identifying typical social behaviour in work settings. Ohtake and Chadsey (1999) examined the depth and breadth of self-disclosure by 21 workers to three types of co-workers and to supported employees with an intellectual disability. These researchers distinguished among three types of work relationships: work acquaintances, work friends, and social friends, who also meet outside the work setting. As previously noted, few workers with an intellectual disability have work friends or social friends. The questionnaire measure used described the extent to which workers talked about themselves to the three types of work contacts, and to supported employees and job coaches in their workplace.

The results were analysed descriptively to show the different types of social relationships, and showed:

- all non-disabled workers had at least one work acquaintance; 91 percent had at least one work friend
- nearly 62 percent of non-disabled workers nominated supported employees as work friends, and 40 percent nominated them as work acquaintances
- none of the supported employees were considered to be social friends by other workers
- workers self-disclosed in greater breadth and depth to their social friends than to work friends and acquaintances
- both intimate and non-intimate topics were disclosed more to social friends.

Ohtake and Chadsey conclude that these findings suggest that self-disclosure by workers with an intellectual disability to their co-workers may help to develop friendships, although it is not clear which comes first. However, the research on social skills intervention focuses on other types of social behaviours. Clearly, any attempts to teach self-disclosure would need to address issues of timing and appropriateness.

Later New Zealand research has also added to these findings, by looking at conversational interaction in the workplace. Holmes and Fillary (2000) examined "small talk" in a number of New Zealand workplaces, by tape-recording 350 hours of conversations. Some of these workplaces included workers with an intellectual disability. A group of volunteers at each workplace taped a range of everyday interactions during a two-week period. They also provided individual, demographic information on those involved.

Analysis of the taped interactions showed how "small talk" fills a range of functions at work, which are primarily social expressions of friendliness and solidarity. Standard small talk topics were usually non-controversial eg, the weather, complaints about work, mention of family, health, out-of-work social activities, sport, appearance. Selecting appropriate topics, individuals, time, and place for small talk are important skills. Successful small talk usually calls for shared knowledge, experiences, and attitudes. Also, gender, status and how well people know each other influences the degree of personal talk and choice of topics. The data showed instances of inappropriate small talk involving

workers with an intellectual disability who "overstepped the bounds of what was considered acceptable" (p 278).

Another problem area was that workers with an intellectual disability did not distinguish between appropriate topics for supervisors versus co-workers, in questions about family.

Another skill required is selecting the appropriate level of detail and length of response. This study found that this was a problem for some workers with an intellectual disability whose response was far too long and detailed to questions such as "How are you?"

Small talk is also a part of certain parts of the work day eg, arriving at work, and failure to take part in this can be interpreted as unfriendly, impolite or bad-humoured. This was a problem for some workers with an intellectual disability. In general, they often failed to "keep their end of the social conversation up" (p 281).

Small talk at work functions to develop and maintain social relationships between employees and is thus an essential component of social integration. However, the complex socio-linguistic skills required are often not realised, and some adults with an intellectual disability have been shown to have difficulties or gaps in these skill areas, especially in extended small talk which moved past simple greetings and responses to direct questions.

In summary, Holmes and Fillary found many examples in New Zealand workplaces, of difficulties with typical social interaction at work for adults with an intellectual disability, limiting the extent of social integration and friendship development. They suggest that these skills can be learned through focussed social skills training both before and during work placement. Strategies suggested are "using the soaps", and role-playing small talk at work, with three basic exercises: practising automatic and brief responses, practising extending small talk, and "spotting the errors". Their research is also described in Holmes, Fillary, McLeod and Stubbe (2000).

The way in which intervention is undertaken may also be important. Lee, Storey, Anderson, Goetz and Zivolich (1997) examined the effects of two different training strategies on the social integration of people with severe disabilities in supported employment. The two training strategies were: use of an outside "job coach; and the use of a selected employee or manager ("mentor") to provide on-the-job training and support. This study also examined how non-disabled employees were trained and supported. Reciprocal interactions between disabled and non-disabled employees were observed over a two-week period. This research found that those disabled employees trained by another employee had significantly more interactions with non-disabled co-workers than those who had an external job coach. However, there were also more interactions between non-disabled employees.

Summary

Supported employment's origins were in the employment of people with severe disabilities. However, this group continues to be under-served. Despite the research evidence, there is still the belief that people with a severe intellectual disability cannot work in a paid job in the community.

While research has shown this is not true, the reality is that most people with severe disabilities who do work are in very part-time, low paid positions, and experience poorer work and social outcomes. However, research has identified some variables which **are** associated with better outcomes for adults with a severe intellectual disability, particularly the importance of co-worker training and involvement.

Employment for adults with severe disabilities is perceived positively by some community stakeholder groups, but the research evidence is limited.

Researchers have called for a greater emphasis on job quality and satisfaction, not just "any job" for adults with a severe intellectual disability. There is considerable evidence to show that adults with severe disabilities can learn job tasks, that systematic intervention to prevent or change problem behaviours can be successful, and that co-workers can learn positive training and intervention strategies. Adults with autistic spectrum disorders can be successfully supported in work, as can those with physical and multiple disabilities.

A large body of research has demonstrated successful strategies for improving the work productivity of adults with an intellectual disability. Both environmental strategies and systematic teaching approaches have been used effectively. Research has also demonstrated the value of teaching workers to monitor and reward their own performance. Such strategies can be successful even with adults who have a severe intellectual disability.

Social skills may sometimes be more important in retaining a job than actual job task skills. Based on the fact that social skills are learned behaviour, a large body of research has demonstrated that adults with an intellectual disability can be taught a range of social skills. Both job-related social skills and general social skills are important.

In addition to promoting job success, social skills are an important part of social integration, another goal of integrated work for adults with an intellectual disability.

Social integration can also be enhanced for workers who have few verbal skills, through the use of communication aids and training for disabled and non-disabled co-workers.

Transition and further education courses can also provide valuable pre-employment training in the social skills and behaviour expected in most job settings.

Social integration at work is a desired outcome of supported employment but does not necessarily occur through physical proximity alone. An increasing body of research has sought to identify strategies to increase social inclusion, but these strategies may need to differ across individual work settings.

Research has identified a number of difficulties faced by workers with an intellectual difficulty who try to make friends and be included in the social environment of their workplace. More attention is being paid to the actual social interactions that typically occur in each work site and the "culture" of that workplace. Once again, intervention strategies involving co-workers may be more successful than training by the job coach, although there are some general skills and behaviours which should be part of high school and transition programmes. Conversational interactions at work can actually involve more

complex cognitive and sociolinguistic skills than are immediately apparent. However, interactions with co-workers can be an important source of enjoyment and friendship.

CHAPTER EIGHT

OTHER MODELS OF EMPLOYMENT SERVICES

Supported employment began with small groups of adults with an intellectual disability working in an open employment setting. This model is often referred to as the "enclave" model. Similar approaches are seen in the use of "mobile work crews", in jobs like janitorial or gardening services. However, individual, rather than group models soon became seen as the preferred model. For example, by 1989, 77.8 percent of individuals were served individually (Kregel and Wehman 1989). Enclave workers formed 9.4 percent of supported workers, and 8.6 percent were mobile work crew members. A "small business" model provided work for 4.2 percent. Kregel and Wehman also found that adults with a severe intellectual disability were over two times more likely to be placed in enclaves than were other workers.

There appears to be very little published research on the use of group models of supported employment. It is not clear whether this is because it has become less frequent or less "fashionable". One of the most frequently cited disadvantages of a "group" model, is the problem of achieving social inclusion, but there appears to be little **research** evidence on this issue.

Work co-operatives

There is some evidence of co-operative work models which employ a number of disabled **and** non-disabled workers. For example, Gosling and Cotterill (2000) describe the emergence in the UK of "social firms", defined as "small businesses, run on a cooperative basis … independent from statutory services, operating in the open labour market" (p 1005).

Gosling and Cotterill outline the characteristics of a social firm used by the Confederation of European Firms, Employment Initiatives and Co-operatives (CEFEC). These characteristics are:

- a social firm is a business created for the employment of people with a disability or other disadvantage in the labour market
- it is a business which uses its market oriented production of goods and services to pursue its social mission
- a significant number of its employees will be people with a disability or other disadvantage in the labour market
- every worker is paid a market-rate wage or salary appropriate to the work whatever their productive capacity
- work opportunities should be equal between disadvantaged and non-disadvantaged employees
- all employees have the same employment rights and obligations. (Gosling and Cotterill 2000: 1005-6).

Gosling and Cotterill evaluated a project which set out to transform four sheltered workshops to a social firm model. The evaluation methods included: semi-structured

interviews with staff, service users, and family members; structured participant observations; and a review of service documents and databases (p 1007).

The original objectives were only partially achieved. The objective was revised to forming of "social enterprises" rather than a "social firm or business". Gosling and Cotterill identified the obstacles to achieving employment for service users, as follows:

- ***The welfare benefits system*** was one of the greatest obstacles, creating a "dependency trap" for the adults with an intellectual disability
- ***The nature of services and experiences of the service system*** (ie, the inability of large day services to offer a flexible, individualised service). However, service users highly valued their experiences in the workshops, viewed their work as a "team" effort, and enjoyed their social relationships
- ***The lack of participation*** by users, carers and staff in the processes in the new initiatives. This resulted in hostility and cynicism towards the project from some staff; the carers felt a lack of regular information, as did service users, who were poorly informed about opportunities for them. Gosling and Cotterill suggest that "it is vital for users, carers and existing staff to be involved with a new service initiative from the outset, and to be offered opportunities to participate in ways which are appropriate to them" (p 1013)
- ***The attitudes of employers*** were a challenge to project staff who only achieved one successful placement in work experience
- ***The need to use community networks and positive role models for service users seeking work***
- ***The rhetoric vs the real impact*** of service and policy initiatives with a perceived lack of change for service users by staff, carers, and the users themselves.

Gosling and Cotterill concluded that, while the project met many of the European criteria, these were largely administrative with no tangible changes in the lives of the adults with an intellectual disability (p 1016).

McWhorter (1998) provides a contrasting picture of a successful change, with a description of a Canadian "co-operative corporation" which was developed out of a sheltered workshop with 27 of the service users who chose to develop this option instead of choosing supported employment. They developed the co-operatives with the help of local business and service leaders. The four criteria for the co-operative were: "ownership, small work groups, a supportive work environment, and real incentives" (p 11). A co-operative was eventually incorporated in which the workers were share owners. Following this initial success, three more co-operatives were developed. All were reported to show a cash surplus, and all workers doubled to tripled their previous productivity rates.

While the workers were not able to earn enough to move off benefits, this reformed work co-operative gave them far more control of their lives and enhanced their dignity and self-esteem (p 11). McWhorter concluded that "co-operatives owned by workers is a model for employment that is feasible in a supportive community" (p 12). They also saw this as a model of **self**-employment.

Neath and Schriner (1998) examined the issue of "empowerment" in employment programmes for people with disabilities, and described positive examples in self-managed

work crews, and co-operative businesses. They critique the notion of empowerment as a characteristic of individuals, which they see as perpetuating a medical, individual model of disability. In contrast, the social model of disability is most consistent with the notion of "social power" or "power **with**" other people who share the same goals or experiences. "Power with" also helps individuals to develop personal power. They claim that:

> *Employment can be made more empowering for people who have severe disabilities by reducing or eliminating 'power over' relationships in the workplace and increasing 'power with' relationships (p 221).*

Neath and Schriner go on to describe examples of self-managed work crews, agency operated businesses, and worker-owned and operated co-operatives.

Self-managed work crews can have benefits in empowering workers in the workplace, and possibly also increasing their income, but they still work in an environment that can disempower workers.

In contrast, provider-operated businesses **can** address employment concerns through employment policies and practices. However, there may be difficulties due to the dual relationship of employer and service provider. They conclude that:

> *the power over aspects of the relationship are probably impossible to eliminate entirely so long as a distinction exists between provider and consumer, or provider-employer and employee (p 223).*

A worker-owned and operated business, however, can eliminate these "power-over" relationships. These co-operatives are growing in developing countries, with 85 examples of co-operatives of people with disabilities examined in a study by Neufeldt and Albright (1995), (cited by Neath and Schriner). They appear to be less common in high income countries with a welfare benefit system.

Neath and Schriner identify potential problems with worker co-operatives of people with disabilities:

- increasing size can lead to "power over" relationships
- understanding of workers over owning shares
- the differences of co-operatives from the prevailing economic systems.

The advantages of worker co-operatives for people with disabilities are seen to lie in their potential to increase the political and economic power of "low status" people, and also to increase the **personal** power of individuals to take more control over their lives.

Self-employment

Self-employment for people with an intellectual disability is emerging as a focus for critical discussion and research. Uditsky, Sannuto and Waters (1996) suggest that self-employment and small business development can provide opportunities for entrepreneurial adults with an intellectual disability. They describe a Self-Employment

Pilot Project which involved seven entrepreneurs with an intellectual disability from a variety of rural and urban locations in Alberta, Canada.

An agreement was reached with government to temporarily waive any benefit disincentives. Each adult was supported by a "Personal Business Advisory Committee" of volunteers. The business ideas were very varied and included:

- a mobile lunch service for offices in a remote business area
- a cookbook for people with limited literacy
- clerical services for small, non-profit agencies.

Partnerships were established with community resources for other entrepreneurs and business ventures. As at the report, three of the seven adults with an intellectual disability were due to launch their small business ventures. Uditsky et al concluded that self-employment should be one of the career options open to adults with an intellectual disability. One of the positive aspects they noted was that these employment options can be developed "without creating a new human service system" (p 82).

Another successful example of self-employment is provided by Davey (1999) who described her daughter's gourmet pasta manufacturing business. This young woman (Vicky) has an intellectual disability and communicates non-verbally. No other services appeared able to meet her needs. The detailed story of Vicky's journey from a very limited and unhappy life to one of significant personal development, empowerment, and achievement, shows what is possible – with very supportive and persistent family members, and highly individualised staff support in her own home.

Neufeldt, Sandys, Fuchs and Logan (1999) provide a descriptive overview of Canadian supported employment and self-directed employment. This review will focus only on self-directed employment.

Self-directed employment was defined as:

> *income generating work where disabled people, to a significant degree, have a prime decision-making role in the kind of work that is done, how time is allocated, what kinds of investment in time and money should be made, and how to allocate revenue generated (Neufeldt 1988 cited in Neufeldt et al 1999).*

These self-directed employment programmes help adults with disabilities to develop small businesses rather than look for wage employment. Neufeldt et al therefore include both self-employment and worker co-operatives in this type of programme. The study covered 10 agencies in four Canadian provinces and selected 20 individual clients (and associated people) from these agencies. Both qualitative and quantitative data were gathered.

The 20 self-employed participants had a variety of disabling conditions, and were involved in a large variety of occupations eg, shop keeping, landscaping. The work co-operatives were limited to document preparation. Most people worked almost fulltime. The **mean** gross income was $15,401 (Canadian) but most earned less than $10,000 per annum. These self-employed workers valued work even though their income was low, primarily because of their sense of independence. Unfortunately, the authors do not

identify how many of those who were self-employed were adults with an intellectual disability. The difficulties with self-employment were: difficulty accessing "start-up" funds; isolation; fluctuation in income. Most chose self-employment for personal reasons, or sometimes because they had been unable to find a job. Overall, these positive and negative experiences reflected other studies of self-employment and small businesses.

The leaders of self-directed employment programmes noted negative attitudes from the business sector **and** from other employment programmes as barriers. Both groups were perceived as "resistant to the idea that self-employment was a feasible option for disabled people" (p 33). Self-directed employment agencies also experienced major problems in accessing funding to provide support, as funding tended to be temporary and "pilot" or "special", rather than ongoing. The major benefits of self-directed employment were seen to be encouraging self-direction, independence, and community integration. Self-employed individuals did express a need for a "one stop" source of information, support, and access to loan funds. They also were concerned about the disincentives (of income support) to succeeding in paid work.

Neufeldt et al call for more research on these options, which are more recent than supported employment and have received little research attention.

Community development

The development of employment programmes – whether supported employment or other models – may also benefit by a greater emphasis on **community development.** For example, Code (1992) described a Canadian collaborative supported employment network, which was employer-driven and involved local community leaders and representatives of all the stakeholders. This collaboration had also led to agencies working together and the active involvement of local businesses.

McIsaac (1991) also called for a re-orientation in approach for staff in employment programmes, from "job developer" to "community economic developer". He defines community economic development as:

> *a professional, planned process which aims to mobilize the economic, social, cultural and spiritual resources of the community for the benefit of all its citizens (p 8).*

McIsaac saw part of the task of a "community developer" being to help adults with an intellectual disability to gain access to generic resources in areas like job creation, human resources development, and small business development (p 9).

Supported self-employment is also now being promoted in the US. Hammis and Griffin (1999) call for supported employment to extend into the growing opportunities in the business world, particularly small businesses, which are supposedly now the fastest growing segment of the business sector. They see possibilities in options such as limited partnerships and supporting sole proprietorships. They conclude:

> *The employment arena is not a finite resource, although the human services perspective has ascribed this characteristic to it. Neither is employment*

development a passive activity. Employment is created through vigorous and relentless creativity, intervention, partnership, collaboration, and hard work (p 21).

Service gaps and the role of day services

With all the positive developments in supporting adults with an intellectual disability in real jobs in the community, one issue appears to have been virtually ignored in the research literature. To date, most of these jobs are part-time, and some adults with an intellectual disability need on-going support when they are not working. What happens when an adult with an intellectual disability is not at work? Are other support services flexible enough to meet these needs? If community participation is the goal for non-work support services, how is support for community participation addressed?

Coates, Donnelly, and Moulton (1999) called for an integrated approach linking all services, resulting in support services which can meet an individual's needs throughout the day and week, and also after retirement from work. These researchers call for a "day support linkage model" to ensure that all the current gaps are addressed, for school leavers right through to elderly adults with an intellectual disability.

One of the dangers of providing formal "day services", particularly if they are facility-based, is that adults with severe disabilities will continue to be denied access to supported employment options. This possibility appears to be an accepted proposition in the paper by Coates et al ie, that adults with severe disabilities need to spend time "getting ready" to work. However, there are clearly needs which supported employment itself cannot meet, including periods of time between jobs/after job breakdown. These issues are often of concern to parents, and are the basis for some of their resistance to employment (outside of sheltered workshops) for their sons and daughters.

Funding systems for different service options may also make it difficult for adults with an intellectual disability to receive support from a number of different agencies or funding streams. Coates et al call for a "co-ordinated, long-term approach to planning to meet the service user's needs and (one which) integrates the person's involvement with a range of program options over their lifetime" (p 9). They propose that the benefits of their model to the adult with an intellectual disability are flexibility, help when it is most needed, specific focussed professional help, and defined pathways for progression (p 18). However, their proposed model appears to have characteristics of the old "continuum" or "readiness" models, which may discriminate against people with more severe disabilities. What is less controversial is their call for better linkages and support, and support services that can fill the gaps that would exist if supported employment was the only available support service. A move towards more individualised "living support" services would also be needed to enable a "linkage model" to be successful.

Henley (2001) reiterates many of the same issues raised by Coates et al regarding the need to address the issue of day services, not only supported employment services. Henley traces the history of day service development in the UK. He describes how some "day care" services became sheltered workshops in the 1950s, when the emphasis changed from "occupation" to "industrial work". Sheltered workshops in the 1960s added the goal of social skills training, particularly for those who **might** find open employment.

With the increasing institutional closures in the 1970s, the number of day centres expanded considerably. They were to be "centres of excellence that would facilitate a two-way flow between the centres and the community" (p 936). The activities provided expanded to include many educational, developmental and recreational options, along with an expansion of the networks of professionals involved. Self-advocacy groups were developed and supported. By the middle of the 1980s, day centres were being reconceptualised as "resource centres", with an emphasis on supporting adults with an intellectual disability to participate in community activities.

Henley is highly critical of policy and service development based on what he sees as a "radical view" of "work for all", or as he puts it, "that paid employment for all people with mental (sic) handicaps was the panacea by which all the ills of traditional service provision could be remedied" (p 941). Henley outlines a number of UK reports which he believes have unjustifiably undermined traditional day services for adults with an intellectual disability, without supporting research evidence to justify the criticisms of them. He cites the proposed closure of many day services with no viable alternatives being offered. It is useful to consider his warning about:

> *the frailty of a system within which policy making decisions are so easily influenced by idealist speculation when there has been insufficient reliable research and evidence to justify radical change (Henley 2001: p 944).*

Even though some of Henley's critique could, no doubt, be challenged, he has raised significant issues which need to be addressed in **any** proposed service development and service changes involving adults with an intellectual disability.

Summary

Research on supported employment has dominated the area of work for adults with an intellectual disability for 15 years. There has thus been little attention to other vocational services even though they continue to provide the majority of adults with an intellectual disability with support and (sometimes) work during the day.

More recently, attention has been directed to alternative work models. Work co-operatives or "social firms" provide an alternative paid work model to individualised, supported employment. Self-managed work crews are another example of a model which enables greater control by people with disabilities themselves.

A different model is a provider-operated business, but the dual provider-employer role may create difficulties.

An option receiving increasing attention is self-employment, previously believed to be unrealistic for adults with an intellectual disability. The available evidence suggests, however, that this may be a creative option for some individuals, given appropriate support.

A further area deserving attention is a community development approach to work for adults with an intellectual disability. This is not a new approach, but appears to be

relatively underused in solving the work needs of this group, probably due to the long history of approaching work needs from a purely individual perspective.

Finally, the role of other “day services” needs to be addressed. There are clearly support needs that still remain to be met for many adults with an intellectual disability who are not in work, or only work part-time. What these services should look like, and how they should link in with supported employment are issues which need to be addressed - in research, and in policy and practice.

CHAPTER NINE

CHANGING SERVICE SYSTEMS

The New Zealand Government's 2001 Strategy, "Pathways to Inclusion", sets out two clear aims for vocational services:

- to increase the participation of people with disabilities in employment
- to increase the participation of people with disabilities in communities.

The primary focus, according to the Minister's foreword, is "on providing genuine employment opportunities for people with disabilities" (p 5). The service changes required to achieve this goal are expected to take place over five years.

New Zealand is relatively slow in adopting a clear policy direction of genuine employment. Policy and service developments, such as supported employment initiatives, have been common in other Western countries since the 1980s. There is therefore a body of research literature which documents and evaluates service changes and outcomes in the area of work for adults with disabilities, particularly those with an intellectual disability. The research evidence can assist in considering questions such as:

- how have other countries succeeded in changing services to increase employment for adults with an intellectual disability?
- what are the barriers to service change?
- is the goal of five years feasible?

The research literature will be reviewed in chronological order, to provide a picture of published outcomes over time, beginning with 1989.

Kregel, Shafer, Wehman and West (1989) report on the outcomes in USA of major systems change grants to convert traditional day programmes to supported employment. During the years 86-88, over $214 million was provided by federal and state agencies for supported employment, a major policy initiative. During 1988, approximately 25,000 people, primarily adults with an intellectual disability, received supported employment services in the 27 states receiving systems change grants. Kregel et al developed a detailed survey questionnaire which examined a broad range of supported employment issues:

- implementation of regulations
- availability of ongoing support services
- conversion of existing facilities/programmes
- participation by people with severe disabilities
- amount and sources of funds (p 285).

The surveys were followed up with structured interviews with each project director. Final state profiles were also sent back for verification before data analysis. The conclusions most pertinent to this review are:

- the 27 states had managed to implement supported employment services in a short time period (2-3 years), however many of the projects had only been in operation for a short time
- substantial fiscal commitments had been made by numbers of federal and state agencies
- identifying sources of long-term support funding was difficult, particularly given the predicted annual increases in these costs
- supported employment had occurred primarily through expansion rather than conversion of existing programmes (ie, the elimination of sheltered workshops had not occurred)
- persons with severe disabilities were not sufficiently represented in the supported employment programmes
- monitoring and quality assurance systems were being developed
- employment was being increasingly viewed as an important outcome by more and more agencies.

Despite these documented changes, Kregel et al noted that supported employment (as at 1989) was still a relatively small programme, compared to other vocational, rehabilitation, and day programmes.

Opportunities for work exist in both the public and private sector, but Rhodes and Drum (1989) noted that, at that time, there were many procedural regulations in the public sector which created barriers to employing people with disabilities through supported employment initiatives. This situation will presumably have changed in the USA since the passing of the Americans with Disabilities Act (1990) which outlawed discrimination on the basis of disability. In New Zealand, the "Mainstream" employment programme is a deliberate approach to hiring people with disabilities within the public sector. Rhodes and Drum identified barriers in 1989, that in New Zealand may constitute indirect discrimination (eg, a written, civil service examination as a prerequisite for selection) and thus breach the Human Rights Amendment Act 2001. Rhodes and Drum found that the basic problem with obtaining jobs for adults with an intellectual disability in many states of the USA was that "civil service practices designed to ensure fairness in hiring create barriers to many persons having severe developmental disabilities (p 203).

West, Revell and Wehman (1992) report the results from a five-year longitudinal study of supported employment initiatives in the USA. The findings of most relevance to this review were:

- 65 percent of all adults receiving supported employment services had an intellectual disability in 1990
- of those adults with an intellectual disability in supported employment, the "degrees" of disability were: 49 percent mild, 36 percent moderate, 12 percent severe or profound
- reported supported employment agencies increased from 324 in 1986 to 2,647 in 1990; most of this growth occurred from 1986-1988
- between 1988-1990, the number of people in individual job placements increased dramatically (21%)
- participants in supported employment earned an average wage of US$102.34 per week; this was only cents above the minimum wage level

- over 80 percent of supported employees were working at least 20 hours per week
- the percentage of supported employees who had severe and profound intellectual disabilities remained at 12 percent over the five years of the study
- the majority of service providers were maintaining segregated day services as their primary focus, merely adding supported employment as an extra option.

As noted, it appeared that the increase in supported employment in the early 1990s reflected new service developments rather than conversion of existing services. However, there were some successful changes within existing agencies. Beare, Severson, Lynch and Schneider (1992) describe a successful change within a small agency that previously provided a segregated day centre service. The outcomes of these changes to supported employment were:

- a community employment rate of 80 percent
- increased income for workers
- increased community integration.

The steps taken by this agency in achieving conversion of their service were:

(i) ***Formalising the philosophy and mission statement for the agency;*** this involved:

- sharing information and obtaining training in supported employment
- obtaining funding to support a supported employment initiative
- comparing the segregated workshop and the supported employment sites, as these developed
- by the end of the fourth year, all board members were committed to complete conversion.

(ii) ***Securing staff commitment to the greatest degree possible;*** barriers to this were:

- fear of change, paternalistic attitude, and the increased effort required; (by 1989 none of the original staff remained). This step involved:

- hiring new staff to lead and implement the supported employment effort
- providing multiple in-service training for staff.

(iii) ***Gaining the support of parents***

- there was initially marked resistance to changing the day programme
- a workshop was held to address parents' concerns
- parents became members of the supported employment advisory council and the agency Board of Directors
- parents were given tours of employment sites and offered 30 to 60-day trial placements for their sons and daughters
- parents participated in making an educational video on supported employment
- the agency set up an Advocacy Council to provide input to the Board.

The agency decided to pursue only two models of supported employment (direct hire and small group enclave) as these approaches involved ongoing interactions with co-workers.

The major **barriers** to successful conversion and how they were dealt with in this service change example were:

- a **"developmental" philosophy** that focussed on getting people "ready" for real jobs; this barrier was addressed by developing a total Board commitment to change at the beginning of the conversion process

- **financial resources.** In this agency, a commitment was made to keeping operating costs the same; some grants were obtained to partially support start-up costs over the first four years only

- **job dissatisfaction.** This was usually due to a simple mismatch between worker and job. A time-limited, on-site assessment solved these problems, with the worker making the choice of whether to continue

- **age-related employment difficulties.** The agency had to develop an alternative programme for people of retired age who preferred social/recreational activities to work

- **co-worker dissatisfaction.** These problems were solved by a "colleague" programme which matched workers with an intellectual disability with non-disabled co-workers (who were offered a nominal reimbursement but this was rejected); this led to increased contact out of work as well

- **interagency collaboration.** The agency developed an Interagency Advisory Council for the supported employment effort; this process led to collaborative problem-solving and a shared commitment to change eg, a process for the transition of high school students to work

- **staff training.** A range of on-going staff training initiatives were undertaken, with this tied to salary and career advancement

- **small agency in a rural area.** This meant a limited job market with smaller businesses, and no large corporations. These factors were used to advantage eg, direct mailing to every employer; accessing media involvement; involving the university

- **transportation.** This was an ongoing issue and workers and staff were part of an ongoing "transport committee" to work on solutions

- **job terminations.** These were viewed as a programme issue, not the person's failure. Only one person chose not to try for another job

- **job benefits.** Workers in enclaves did not enjoy the same benefits as those in individual jobs, and this problem was not solved.

This description of service change has been reported in some detail to provide a picture of the type of challenges faced by service providers who wish to change from a day service/sheltered work programme to supported employment. What has not been included

are the actual requirements of implementing supported employment, as this has already been covered in a previous section. The report finishes with practical recommendations for other service providers (p177-8).

The outcomes for adults with an intellectual disability in this agency over the five year period were:

- from no one in paid employment to 80 percent in real work, 69 percent in fulltime work
- a 1,200 percent increase in the average salary earned by workers over the five years
- by 1989, the costs for support per worker were less than in 1984
- workers were employed in a variety of jobs
- of the 51 people in integrated work, 49 percent were still in their original job; one person had been employed for 55 months.

By 1992, the promises of supported employment in USA had not been fulfilled. Braddock (1994) reported that only an average of 18 percent of adults with an intellectual disability were supported in integrated work settings. Most resources were still going into segregated vocational settings. Albin, Rhodes and Mank (1994) surveyed eight organisations to explore the reasons for the relative lack of progress in changing to supported employment services. They also reviewed published reports of agency changeovers ie, "the total reallocation of agency resources from segregated, facility-based to integrated, community employment" (p 106).

Albin et al found very few published reports and very few organisations which aspired to or achieved total changeover. As earlier studies showed, supported employment was usually an additional service option, rather than a replacement for existing segregated services. The expected shift in resources was not occurring.

In-depth telephone interviews were conducted with directors of eight organisations from four states that were pursuing changeover. The agencies served from 30 to 100 individuals. Three had achieved complete changeover. The agencies reported on working on changeover from four to 10 years. The results are reported under five questions, as follows:

- **Why did the organisations choose to change?** It was clearly a decision based on values, a belief that community employment was the best option for adults with an intellectual disability. Availability of funds was listed as the reason by only one organisation.

- **What were the barriers to changeover?** Those mentioned most often were:

    - the cost of operating two services at once
    - lack of skilled staff
    - unfriendly funding systems
    - lack of community awareness
    - contradictory policies, regulations, and messages from funders
    - barriers with other local agencies
    - the need to build consensus (p 108).

- **What factors contributed to success?** The factors identified were:

  - leadership
  - staff involvement in decision-making
  - incentive grant funding
  - staff training and professional assistance
  - demand from service users
  - "collective momentum"
  - decrease in staff turner
  - organisation credibility (p 109).

- **What aspects required the most change?** The issues identified included broad aspects such as organisational structure, culture, and values, as well as specific changes in staff roles and skills (p 109).

- **What advantages and disadvantages were experienced?** The major positive outcomes were the increased opportunities for adults with an intellectual disability. Improvements in organisation and staff quality were also noted.

Albin et al identify two major challenges to making such significant service change:

- dealing with **fundamental conflicts** in vision, values, and assumptions between facility-based and community employment services, particularly changing from a "readiness" model to one which views employment as the immediate goal. As Albin et al put it:

  Organisations pursuing changeover are caught between moving into the future and being restrained by those who wish to hold on to the past (p 111).

- the strain of operating both facility and supported employment programmes (p 111).

Albin et al provide recommendations to policy makers and funders which could reduce some of the barriers to changing services. The direction of these recommendations are:

> *… policymakers and funders would provide leadership on the mission, provide a catalyst for changes, focus on outcomes rather than on regulating the processes, and move toward more and more local control (p 113).*

The pessimism in some of the earlier follow-up studies is only relieved to some degree in later reports. McGaughey, Kiernan, McNally, Gilmore and Keith (1995a) report an increase in adults with disabilities in supported employment from 17 percent in 1986 to 30 percent in 1991. However, over the same period the average number of people in segregated vocational services also increased. McGaughey et al surveyed a national (US) random sample of 643 service-providers in 20 states regarding services provided in 1991, and also examined service outcomes from integrated **and** segregated services.

In spite of the expansion of integrated employment services since 1986, more than half of the providers had started, maintained or expanded their segregated programmes over the

five-year period. Moreover, almost all providers said they were not planning to change their pattern of segregated services in the future. Only 2-3 percent actually planned to close a segregated service. Thus the picture continues of integrated services simply being added as a supplement rather than resulting in conversion of a segregated vocational service system. Even though the increase of persons in integrated work (30%) is encouraging, McGaughey et al point out that the converse is that 70 percent were still spending their days in segregated programmes. They note that "the existence of a dual service system appears to be more a reality now than five years ago (p 281)." This situation is in contrast to residential service changes which led to a significant reduction in large institutions as community services increased. McGaughey et al point out that government practices have a major role to play in supporting change:

> *For integrated employment to replace, rather than simply to supplement, the segregated system, state and federal practices must be in line with the values of opportunity, inclusion, and empowerment and must support movement toward conversion of the segregated system (p 283).*

Some of the actions suggested are:

- creating fiscal incentives
- adopting flexible regulations etc. that support inclusion
- developing service planning strategies
- providing training and technical assistance
- approving higher rates of funding for integrated services
- encouraging organisations to adopt total quality management principles.

Another report by McGaughey, Kiernan, McNally and Gilmore (1995b) suggests additional strategies to promote service change, including:

- directing new service users away from segregated programmes
- examining why individuals are still entering segregated programmes (eg, is it due to a lack of integrated employment services?)
- tying integrated employment funding to a commitment to phase out facility-based services
- providing bonuses for moving individuals from segregated programmes to integrated work.

Other researchers saw the "dual system" situation in the 1990s as a critical "crossroads" after a decade of growth of supported employment services.

> *If left unaddressed, funding pressures and programmatic obstacles will confine supported employment to marginal status as a small, optional program that continues to be dwarfed by our nation's entrenched network of workshops and activity centers (p 287).*

Wehman and Kregel (1995) identified four major challenges facing the movement for inclusion. These four challenges were identified through multiple methods and sources:

- convert day programmes to integrated employment services

- increase the capacity of integrated employment services
- expand consumer choices and self-determination
- promote meaningful employment outcomes (p 288).

Wehman and Kregel provide a detailed outline of the multiple solutions required to address these challenges, reiterating the suggestions of previous researchers. These include:

- changing legislation where necessary
- affirming government commitment to supported employment
- ceasing to offer segregated options for new service users
- requiring local communities to develop plans
- eliminating disincentives to service conversion
- providing high quality resources to agencies trying to convert their services
- developing new and creative funding sources to support people with severe disabilities, and providing financial incentives to agencies that serve this group
- supporting research and demonstration initiatives
- ensuring greater involvement of consumers in the decision-making processes around employment
- developing more "consumer-driven" models of supported employment
- enabling more job mobility and career advancement for users of supported employment services; the focus should be "on careers, not jobs" (p 295)
- increasing secondary school and transition services' focus on career development
- developing strategies to overcome negative attitudes in the workplace
- professionals working with consumers and their families to advocate for change.

Despite the apparent lack of progress in converting from segregated to integrated services in the early 1990s, organisations in the US have continued to "convert". Rogan, Rinne and Held (1997) report on a study in Indiana of agencies undergoing "changeover". The key barriers to change identified by agencies were similar to earlier studies, but there were some differences in rank ordering:

- funding
- negative attitudes of key stakeholders
- regulations
- lack of expertise
- leadership
- full day supports
- transportation
- social security disincentives
- operating dual systems.

The UK also underwent similar experiences to the US in terms of promotion of integrated employment, but this movement was probably 5-10 years later eg, the 1990 Real Jobs Initiative. Phillips (1998) reports on progress five years after the 1990 Real Jobs Initiative. The recommendations from this project appeared to have been only partially achieved. There was a serious lack of basic data on which to evaluate progress, with a significant need for research. Similar to the US, a growth in supported employment for

people with mental illness was apparent, as well as services providing for a broad range of people with varying disabilities. Phillips describes the changes in the service sector as "opportunistic growth rather than planned strategy (p 11)". He identifies a significant need for a new "technical assistance programme" to help agencies to convert from segregated services.

Another UK writer (Steele 1996) claimed that the major barrier in enabling more adults with an intellectual disability to work, and to work longer hours, are **systems** barriers. For example, adults who live in residential services have to work part-time or they lose their accommodation funding. The whole benefit and employment system is based on the assumption that adults with an intellectual disability are "unable to work". As Steele notes, "an entire industry has grown up around the unemployed, permanent training status of learning disabled people" (p 16), ie, people with an intellectual disability.

Another focus of criticism by Steele is the "wholesale" acceptance of a US model of supported employment, in which the role of the job coach is far too complex and broad. She suggests closer working and collaboration with staff in related services.

The complexity of funding streams for supported employment in the UK was also seen as placing barriers to supporting people with severe disabilities in work. She concludes:

> *It needs to be said, supporting people with significant disabilities is very different to supporting people who can fast-track. It takes more creativity to find the right job and establish the appropriate support; it requires more skill when negotiating the position with employers; not to mention the resilience to handle more rejections, and it costs more. The benefit issue is far more restricted, the jobs are not real, and the staff burn out quicker.*
>
> *This does not mean that we should not do everything possible to serve all people who want jobs, but that we should be open about the obstacles (p 18).*

By 1998 in the US, research was still reporting on the continuing difficulties in converting segregated services to supported employment. West, Revell and Wehman (1998) focussed specifically on 385 randomly selected agencies that **were** trying to convert to supported employment. Data were collected by the use of in-depth telephone surveys. Of the 385 agencies, 22.6 percent had converted, while 60.8 percent still provided both types of services. The conversion process had been going on, on average, for 5.2 years. Over this time, agencies had increased the number of people in supported employment by 24.7 percent and the proportional funding by 29.8 percent.

The three most significant barriers to conversion were:

- family reluctance (36.6%)
- resistance from agency staff (24.4%)
- limited funds.

Most agencies had clearly experienced a very lengthy and difficult change process. Agencies reported that the **most** supportive groups were the Board; consumers, and funding agencies, while families were the **least** supportive. Although more than one-third of agencies had managed to move a proportion of their resources to supported

employment, the degree of change was clearly "not that which was hoped for in the 1980s (p 244)". As West et al point out:

> *Many families, rehabilitation facilities, and communities have invested deeply, financially and emotionally, in segregated programs and resist efforts to downsize or eliminate them (p 245).*

There have been strong calls for service change, as a simple human rights issue. Research evidence has clearly demonstrated the significant benefits of paid, integrated work for adults with an intellectual disability. Wiener-Zivolich and Zivolich (1995) claim:

> *Individuals with disabilities should no longer have to wait in segregation, unemployment, welfare, and poverty, if these management personnel cannot make the required behavioral and managerial changes to implement integrated employment services…*
>
> *… Persons with severe disabilities consistently have stated that they want jobs… Why do they continue to wait, 10 years later for the segregation industry to hear and respond to this request? (p 311).*

These researchers call for a radical new approach to fostering change. They suggest providing financial grants to private sector employers to employ, train, and integrate people with an intellectual disability into the workforce. Such a move, they claim, would also have a substantial positive economic effect, by returning every dollar spent through savings on segregated programmes, benefit reductions, and new tax paid by adults with an intellectual disability.

By 1999, the major issues around vocational services in the US, did not appear to have changed greatly. Wehman, West and Kregel (1999) described a steady growth since 1986 in the number of supported employment programmes. However, they also noted the continuing issues of low pay, few people with severe disabilities in work, national unemployment rates of 65 percent for people with disabilities, and the huge numbers of adults still in segregated, day programmes. Wehman et al identify 10 key research and policy issues which, they believe, must receive attention in order to achieve the early promise of supported employment initiatives:

- consumer choice and self-determination
- enhancing meaningful employment outcomes (eg, pay rates, employee benefits, career options, social integration, job retention)
- addressing employer needs and perceptions
- fostering natural supports in the workplace
- assessing cost-benefits more intensively
- meeting the needs of unserved/under-served groups (ie, people with the most severe intellectual disabilities; atypical disability groups such as cerebral palsy, brain injury, autism, and deaf blindness; racial and ethnic minorities and women; people on waiting lists for services)
- addressing the need for extended (long-term) services
- bringing about systems change or organisational development, through policy consensus, financial incentives, and technical support

- undertaking thorough and informed policy analysis, which evaluates the actual consequences of any changes (eg, in regulations, funding processes etc.)
- identifying and fostering effective cooperative agreements and interagency collaboration.

McGaughey and Mank (1999) analysed US states' outcomes in implementing supported employment. They outline the history of complex legislative and funding systems in the US to promote supported employment and encourage service change. They note the problems identified by other researchers:

- low percentages of persons with severe disabilities
- funding disincentives
- rate inequities
- entrenchment of some facility-based services
- waiting lists of students leaving school (p 57).

McGaughey and Mank present a conceptual framework for analysing the factors which affect systems change in a US state:

- political factors (ie, political culture, liberalism, political competition, grassroots advocacy)
- economic factors (ie, employment rate, supported employment spending ratio to per capita income; federal spending ratio, tax ratio)
- demographic factors (ie, state population, degree of urbanisation, degree of industrialisation) (Table 1: p 58).

McGaughey and Mank analysed a complex array of data on supported employment from all states except two, which had missing data on outcome measures. Socio-political and demographic characteristics were also examined for their relationship to outcomes.

The results showed large variability across states in supported employment rates, from 13 to 165 per 100,000 persons. States showing the greatest changes over time in supported employment services also showed the highest rates in 1995.

They also found that those states which had the highest extended employment rates **and** served the most people with a severe intellectual disability or long-term mental illness also showed:

- a significantly higher proportion of supported employment funding to per capita income
- significantly higher scores on the policy liberalism index
- significantly higher overall state employment rates (p 165).

These results confirm McCaughey and Mank's conceptual outline of factors influencing supported employment system change. The most significant economic predictor was state fiscal commitment to supported employment. Policy "liberalism" was also important, and the researchers note that the 16 "strongest" states were also more likely to have stronger anti-discrimination employment legislation (p 67). Even with lower per-capita incomes, five states achieved strong supported employment outcomes. Population was not a

predictor of outcomes. They concluded that "income differentials appear to affect supported employment rates less than political inclinations (p 68)".

Mank (2000) reiterates the lack of comprehensive systems change in vocational services for adults with an intellectual disability. He notes that the research literature suggests that "sustained and widespread change is more likely in states where the federal government mandates and funds the change and takes longer and is less widespread if there are no financial benefits to states (p 17)". Mank reports on a study of those states which had consistently implemented supported employment at a higher rate. The variables related to this success included:

- being one of the first 10 states to receive systems change grants
- having received incentive funding for more than five years
- being more likely to have greater funding invested in supported employment relative to per capita income
- higher overall employment rates
- higher rates of people with mental illness in supported employment.

Mank suggests that a more relevant question than "Has the system changed?" is "Is the system changing?"

Butterworth and Gilmore (2000) provide a concise analysis of employment trends in opportunities and supports for adults with an intellectual disability. They note that in the ten years from 1987 to 1997, the employment rate for people with disabilities **declined,** despite the times of economic boom. These declines were 8.5 percent for men and 5.6 percent for women. Data on poverty for working adults with disabilities also shows much lower median annual earnings than non-disabled workers. In terms of family income, 25 percent of men with disabilities and 32 percent of women with disabilities lived in families whose income was below the poverty line.

The major trends identified by Butterworth and Gilmore (over eight years to 1996) are:

- services expanded (both day and employment services) by 40 percent
- supported employment increased by over 200 percent
- there was continued growth in facility-based and non-work options by 12 percent
- individuals with disabilities were increasingly using multiple service options simultaneously
- community-based (community integration) non-work options had increased to represent 16 percent of overall services
- the total **number** of adults with an intellectual disability "completing" or "exiting" vocational services remained steady. In 1998, 86 percent of successful "closures" were in competitive employment, while 12 percent were in sheltered employment
- the number and percentage of people entering competitive employment has increased steadily
- there was a significant **decline** in real, mean weekly earnings for adults with an intellectual disability by 51 percent; the mean number of hours worked had also declined; these decreases must affect quality-of-life

- supported employment services were still not fully integrated in mainstream service funding.

Butterworth and Gilmore conclude that "despite positive change, the majority of service system resources continue to support facility-based or other non-work services (p 7)".

The US continues to introduce legislative changes to support adults with disabilities who want to work. Butterworth, Hoff, Varney and Marrone (2001) outline the provisions of the Ticket to Work and Work Incentives Improvement Act 1999. This Act offers adults with disabilities greater potential control over their employment supports.

The basic idea of this Act allows people to select their own employment service provider who is then paid by Social Security **only** for a successful outcome, ie, getting a job which enables the person to get off a benefit. The programme is being phased in over the three years from 2001-2004. Participation in the programme is voluntary.

Butterworth et al express concerns at the failure of this new programme to provide enough resources to cover the job search and job support needs of people with severe disabilities.

Supported employment can be seen as a new service paradigm, similar to the model of "supported living", with a focus on supporting individuals in the job or home of their choice. Saloviita (2000) analyses the difficulties that arise with new service paradigms that are incompatible with traditional services. In Finland, in 1995, considerable resources were put into promoting supported employment service development. However, evaluation of progress was extremely disappointing, with few people in jobs, and those that were working receiving extremely low pay and remaining on benefits.

The service providers claimed that the main barriers to success were "the ignorance and prejudice of the employers .. or difficulties in combining earnings with state benefits (p 92)." However, Saloviita describes the conflict between ideas governing traditional services with the ideas underpinning supported employment, and the inherent incompatibility between these two opposing sets of ideas. Because it was existing organisations which undertook to provide supported employment (as an additional service) the new paradigm simply became absorbed into the old one, which asserted that people with an intellectual disability were incapable of "real work". The new paradigm challenged the model and purpose of sheltered workshops, and by extension, other types of segregated services – a "legitimation crisis" for these existing service organisations.

The solution to this crisis was to reinterpret supported employment to make it more compatible with existing services – for example, it was described as a "method", thus ignoring the fact that entirely new goals were essential in this new paradigm. Supported employment was then deemed to apply to only a few people, and included non-paid work.

The other way the legitimation crisis was handled was to "decouple" it from organisational control eg, by leaving it to individual staff choice and personal enthusiasm.

The end result for Finland appears to be failure to bring about any real change for adults with an intellectual disability in their opportunities for "real work".

The "failures" of the supported employment movement to bring about the degree of service change predicted has also been interpreted as reflecting the reality that some adults with an intellectual disability need segregated settings. Murphy et al (2002), however, argue that the major obstacles to change are systemic – at least as much as issues about community employment itself (p36). The issues they see as critical to service change are:

- the need for multiple, timely job opportunities
- the provision of integrated, interim supports
- the anxieties and barriers resulting from retaining dual services
- comprehensive systems change which promotes participant-controlled services, in which reform does not depend so much on **agency** change.

Finally, Murphy and Rogan (1995) provide a comprehensive text on conversion of services from sheltered to integrated work. While the examples provided are from the US, they set out 14 broad lessons which may be useful to New Zealand service providers.

- Build support for change from within the agency.
- Define clearly the values that drive the agency's vision and mission.
- Ensure that internal leadership provides support, encouragement, and guidance throughout the process of change.
- Plan to act, and act on plans.
- Consider the use of outside consultants to plan for and guide change.
- Invest heavily in staff development and support.
- Strive for a flat organisation with most staff providing direct services.
- Change the agency's image to match its values, vision, and mission.
- Define, demonstrate, and celebrate large as well as small successes.
- Pursue creative, alternative funding options.
- Involve key stakeholders from the beginning.
- Unload **sunk costs** (ie, investments in capital equipment and buildings, known by some as the "edifice complex").
- Terminate facility admissions and backfilling as soon as possible.
- Do not wait for everything to be in place before beginning the process of change (Murphy and Rogan 1995: p 180).

Summary

Other Western countries have experienced and researched service change in vocational/employment services for adults with an intellectual disability over a period of almost 15 years. The major changes have involved moving from traditional day centres and sheltered workshops to supported employment services.

Research demonstrates how difficult it is to change service systems, and how much of the change in employment services has been the growth of new services rather than the replacement of old ones – resulting in the persistence of a dual system of services.

In other Western countries, particularly in the US, significant resources and legislative changes have been provided as incentives to change, but, even with these government

directions and resources, change has been less successful than expected, for many organisations. However, increasing numbers of adults with an intellectual disability are in paid work, due to supported employment initiatives.

The barriers to change identified in research include regulatory, resource, organisational, and attitudinal factors.

Overseas research on service change provides a number of relevant findings for New Zealand policymakers and service providers. Service change is complex, costly, often very difficult to achieve, and can be lengthy – but it is possible. The established benefits to adults with an intellectual disability of quality transition and supported employment programmes provide the rationale for why services should change. Government has a significant part to play in promoting, requiring, monitoring and rewarding service change.

CHAPTER TEN

CONCLUSIONS

This review of work for adults with an intellectual disability began with an international assertion that people with disabilities have a right to work and that work is the route to economic and social integration. But the facts are that most adults with an intellectual disability are poor, are deemed unable to work, and spend their days in segregated services, some of which provide some "sheltered work", for no or minimal pay.

Do adults with an intellectual disability want to work? The available evidence suggests that they aspire to work for the same reasons as other people and that they like working in "real" paid jobs in the community. So what prevents them from working? In brief, we do. As in other areas of their lives, adults with an intellectual disability usually require individualised support to get a job, learn how to do it, how to get on with co-workers, keep the job, and have a career.

A large body of research evidence has shown how the model of vocational services known as "supported employment" can enable adults with an intellectual disability to work in paid jobs in ordinary work settings, with positive economic, social, and personal outcomes. Providing quality supported employment services, however, calls for a range of expertise and skills which are different from those used in segregated and sheltered employment. Also, while the evidence shows that supported employment can be effective for people with severe disabilities as well, only a small proportion of this group has access to supported employment services.

The evidence that is available also supports the cost-benefits and cost-effectiveness of supported employment services over time. At the same time, the evidence from countries which have sought to change their vocational service system shows that this is a difficult and complex endeavour.

Lack of New Zealand disability research

The enormous scope of relevant research can be seen from this limited review. However, almost all of it is American, with some from the UK, Canada, and Australia. Very little published New Zealand research was located, but what was found was very useful.

Research is also critical to provide a greater voice for adults with an intellectual disability themselves. Their own work preferences will differ, and it is too easy to continue the old mistake of making everyone "fit" into one model of work or service provision. On the other hand, if they have no opportunities to experience different lives, including work, they are often unable to express informed preferences.

> *… the very notion of work "support" as something that enhances the employment success of an individual with a disability is meaningful only if it responds to the aspirations, abilities and enthusiasms of the consumer, by whom success is measured…*

> *… The consumer focus is not a "new" focus, rather it represents a salutory return to fundamental supported employment values and practices, which put the success and interests of the person with disability first. Only with the collection of empirical data and experience, accumulated over time, has it become possible to determine which strategies and supports help realise the promise of supported employment for consumer success, choice, and satisfaction (Wehman and Bricout 1999: p 17).*

The Best Practice Guidelines for Vocational and Support Services recently published by VASS (Aiming for Excellence 2001) provide a set of clear values for policy makers and service providers, which maintain a focus on the person with an intellectual disability:

> *Everyone's journey is important.*
> *Ko te kai rapu, ko ia te kite.*
>
> *My life has purpose.*
> *Ka tikanga toku ora.*
>
> *My life has meaning for me.*
> *Ka putake ora moku.*
>
> *I am supported to achieve my dreams.*
> *Whakawaihanga te pai o nga tangata. (p 6-10).*

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