

Education for adults with an intellectual disability (including transition to adulthood)

**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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PLAIN LANGUAGE SUMMARY – TRANSITION

What is transition?

The word transition is used a lot within the disability field. Transition means what happens when students with an intellectual disability move from school and start to live more adult lives as part of the community. The transition from school to becoming an adult is difficult for all young people but sometimes this time of life is even harder for young people with an intellectual disability.

What is transition planning?

Transition planning is the way that young adults are supported or helped to move from school to adult lives in the community. Positive transition planning supports people in the following areas of their lives; employment; recreation; education; self-determination; and community living.

When a young person is involved in transition planning their views and interests are the most important things to consider. Transition planning meetings usually involve teachers, careers advisers, disability service providers, and parents, as well as young people with an intellectual disability themselves.

Why is transition planning important?

When young people with an intellectual disability finish school they often find it hard to know what they should do next, or even what services or opportunities are available to them. They can also have difficulty knowing what kind of benefits they are allowed. Transition planning helps young people and their families get information so they can make choices about the future.

What do young people with an intellectual disability have to say about transition?

Researchers have found that young people with an intellectual disability have different views and feelings about leaving school. Some young people cannot wait to leave school, while other people can feel scared or anxious about this big life change. Young people with an intellectual disability often have clear goals for the future and most want to get a job. Getting a job and earning money is seen as a way of becoming more independent with many young people planning to leave home when they have earned some money.

When asked how they have found transition planning meetings, some young people have said that transition planning is quite negative. This is because meetings often focus on the things that they cannot do, rather than the things they can. Other young people with an intellectual disability have said they have learned a lot from the process of being involved in their own planning meetings. It is important that young people feel comfortable “to have their say” in these meetings, and it is also important that information is given to them in a way that they can understand.

What do parents have to say about transition planning?

Parents find transition planning useful because it helps them to support their sons and daughters as they leave school. Parents have one main worry for their children with an intellectual disability as they leave school – that they will have real choices for employment, education, and supported living.

What kinds of transition projects are there?

Most transition projects focus on work and looking at ways to help young people with an intellectual disability to find jobs. Research has shown that it is important for young people to have “real” work experience as well as job skills training as it helps them to learn the skills they need more quickly and easily.

When young people have been part of a transition planning process they usually find it easier to move from school to a more adult way of life in the community. Researchers have also found these young people often get jobs more quickly than other people with an intellectual disability who have not had transition planning.

Best practice – What is good transition planning?

- Transition planning is not just about work, it is also adult education, social relationships, supported living, and community participation.
- Transition planning is supposed to be positive. Young people with an intellectual disability must be in control of their own transition process.
- It is important that young people with an intellectual disability learn self-determination skills or how to make choices and decisions for themselves. Researchers have found that being able to make their own choices and decisions helps people to have more positive adult lives.
- Opportunity for adult education must be part of transition planning.
- It is important for young people with an intellectual disability to have “real”, paid work. This is seen as part of becoming an adult.
- There needs to be a flexible benefit system so that young people do not **lose** money if they try to get a job.
- There needs to be more choices and options for young adults as they leave school.
- Special attention needs to be paid to transition planning for young adults with an intellectual disability who have high support needs.

- Schools, adult disability service providers, employers, and adult education services need to get together during the process of transition planning. This is so that young people with an intellectual disability know about all their options for the future as they leave school.

PLAIN LANGUAGE SUMMARY – ADULT EDUCATION

What is adult education?

Adult education means the learning that adults with an intellectual disability do after they leave school. They may learn new skills so that they can get the type of job they want, or to help them become more independent in the community. They may go to a polytechnic, or a university, or they may have opportunities for adult education within disability services. Sometimes adult education is called post secondary education.

In the past, most education for people with an intellectual disability has been provided away from other people. Now people with disabilities and others involved in the disability field are saying that adults should have the opportunity to attend the same courses as people who do not have disabilities. It is important that people with an intellectual disability have access to education at the same times in their lives as other people. For example, they should not have to stay at high school when other students of the same age have already left school to further their education or to get a job.

What types of adult education are there?

Most adult education programmes focus on work skills, work experience, or life skills. Overseas, there are a number of adult education projects that allow people with an intellectual disability to experience university life. In these education programmes adults take part in courses, and in some cases, get to live on campus with other non-disabled students. This is an important part of adult education as it allows disabled students to meet more people and make new friends.

While adults with an intellectual disability can sometimes get to take part in a particular course or training programme that they are interested in, they do not usually get a formal qualification after taking part. This is because people providing the education programme or course do not know how to change the course to suit the learning needs of students with an intellectual disability. Researchers have found that in some cases people with disabilities are included within education classes or courses because of what other non-disabled students can learn from them. This should not be the reason for allowing adults with an intellectual disability to take part in these courses.

What is literacy education?

Literacy education is a particular type of adult education with helps people to learn how to read and write. Literacy is very important to adults with an intellectual disability because it helps them to lead more independent lives. It is easier to learn how to read and write if the person doing the learning identifies their own goals or says what it is that they want to learn about. Sometimes it is difficult to get accepted into a literacy course because other people believe that adults with an intellectual disability cannot learn how to read and write.

Barriers to adult education – What stops adults with an intellectual disability from having the chance to learn?

There are many things that stop adults with an intellectual disability from learning but one of the biggest problems is other people believe that they are unable to learn or to achieve academic standards that other non-disabled students can achieve. In order for adults with an intellectual disability to achieve “real” educational opportunities these attitudes must be challenged.

How can adult education for adults with an intellectual disability be achieved in New Zealand?

- The government needs to think about this issue and plan ways in which adults with an intellectual disability could have more educational choices.
- Adults with an intellectual disability themselves need to say **what** it is they want to learn and **where** they want to learn.
- The opportunity for on-going education needs to be part of transition planning.
- Adult education courses and programmes need to be flexible so that adults with an intellectual disability can gain useful, recognised qualifications.
- Adult education for adults with an intellectual disability should be held in the same places that it is for other non-disabled adult students.
- The learning needs of older adults and adults with high support needs are important and need to be considered when planning adult education for adults with an intellectual disability.
- Literacy is important to all people but it is particularly important for adults with an intellectual disability as literacy skills help them to become more independent. More adult literacy programmes which include adults with an intellectual disability are needed in New Zealand.

YOUNG PEOPLE WITH AN INTELLECTUAL DISABILITY AND THE TRANSITION INTO ADULTHOOD

Introduction

This review contains two distinct but interrelated sections. The first section contained in this review is **Transition and Young Adults with an Intellectual Disability**. The second section included is titled **Adult Education for Adults with an Intellectual Disability**.

The first section of this review is focused on young people with an intellectual disability and the transition into adulthood. While previous reviews conducted for the purposes of this National Health Committee Project have focused on **adults** with an intellectual disability, transition planning and issues related to this process generally begin to occur during the secondary school years. For this reason, the section of the review of Transition contains information relating to young people under the age of 21 years (the age to which high school education in New Zealand for young people with an intellectual disability can be provided). It is important to include this information on transition and transition planning for younger people together with “adult education” as both areas are directly relevant to the adult experiences of men and women with an intellectual disability.

The second section of the review explores the area of Adult Education for Adults with an Intellectual Disability. Opportunity for further education is one aspect of transition and transition related planning therefore links between the two areas are highlighted where relevant. However, as it is just one aspect of adulthood we have made the decision to include Adult Education as a separate section rather than including it within the review of transition. Other areas of adult life that are also integral to the transition area have been covered in other reviews (ie, relationships; community participation; support for daily living; employment; and income).

Young people with an intellectual disability and the transition into adulthood

The transition into adulthood is an exciting time when young people can dream of the future and set goals. For us all, goals and dreams can be both personal and public, involving friends, family, partners, lovers, travel, employment and more. This is ordinary and everyday, whether you call it transition, youth, growing up, or adolescence. However the experience of a young disabled person preparing for adult life is often one of a struggle with systems that seem only to lead to dependence and few choices. Families of the young person often consider the transition from school to adult life as a time of risk when the need to protect and care contradict the feelings of wanting their loved one to be independent and free to experiment (Dobson and Jay 2000: p 18).

What is transition?

Transition is a term that has been used more and more commonly in the field of intellectual disability research and practice over the past twenty years. In the disability context, transition is generally accepted to refer to the process by which students with disabilities (including those with an intellectual disability) move from the school environment to productive adult lives in the community (Lichtenstein and Nisbet 1992).

There are a number of different ways of theorising the transition to adulthood. Conceptualisations of the notion of transition to adulthood in the general literature have predominantly focused on two areas: (a) models based on life phases (child to adult); and (b) models based on institutional status transition. In terms of institutional status transition, three specific transitions are usually highlighted: school to work; housing (moving out of the family home); and domestic (movement from 'family of origin' to 'family of destination') (Mitchell 1999). While the transition from education to adulthood can be difficult for young people, all three of these transitions can often prove difficult to achieve or even elusive to young adults with an intellectual disability.

The issue of citizenship had also been identified as integral to the notion of transition to adulthood. Citizenship – the process of young people becoming full and active 'citizens' is not something that all young people achieve at the same age or stage in life. Young people with an intellectual disability often experience social or structural inequalities which can mean that their opportunity to 'achieve' citizenship is reduced or disadvantaged. Tisdall (1994) advocates for a transitional model based on citizenship where the debate over what constitutes successful transition would be replaced with an emphasis on young people with an intellectual disability themselves. She also highlights the need for greater links between this group of young people and advocacy organisations.

Mitchell (1999) defines the issues that may impact on young people with an intellectual disability as they experience the transition to adult life.

Hence it is important to understand that social relationships, attitudes and the physical environment that disabled young people face in their everyday lives, guides their personal experience of dependence and independence. In light of this one must recognize that past youth transition models may not always be the most appropriate means to explore disabled young people's transition towards adulthood. Their presentation of transition is very precise and linear and thus over simplistic. The transition to adulthood is, however, a complex and complicated process for young people in general, and disabled young people in particular, and is a much more complex process than traditional models would suggest (p 755).

What is transition planning?

Transition is a multifaceted component of the education process. The student is reaching the age of majority; the family is dealing with the change in perception of their son or daughter from child to adult. This process of change and growth begins in early childhood with that first graduation from early intervention

services and continues past the window of time that the student will be in public school. Transition services at the middle school and high school level, appropriately planned and implemented, prepares the student and family to begin yet another stage of life – adult life – in the home and in the community (Rosenberg and Bolton 2001: p 23).

A central focus of this review is the exploration and discussion of the process of transition planning for young adults with an intellectual disability. Transition planning is the process by which young adults are assisted or supported to move from the school environment into adult roles within the community. The focal point of the transition process is the development of a formal, individualised transition plan (Wehman, Kregel and Barcus 1985). Transition planning incorporates a focus on post-school activities including: employment; recreation; post secondary education, self determination; and community living and participation (Thoma, Rogan and Baker 2001).

It is widely recognised that within the American context the 1990 Individuals with Disabilities Education Act (IDEA) broadened the scope of special education by adding a requirement that transition planning be incorporated into the individualised education planning (IEP) process (Furney, Hasazi and DeStefano 1997).

Transition planning is required to take into account student views, preferences, and interests. (However research shows that this does not always occur – see later in this review.) The concept of self-determination has recently been identified as important to consider when considering transition and transition planning (Thoma, Rogan and Baker 2001). For example Wehmeyer (1998) is of the view that self-determination should be at the heart of transition planning and initiatives. Wehmeyer proposes that self-determination and positive adult outcomes are causally linked therefore self-determination is an important educational goal if youth with disabilities are to enjoy more positive adult lives. Furthermore, the concept of self-determination must be integral to transition planning and initiatives if student's preferences and interests are to be incorporated.

As well as involving students themselves, transition planning efforts usually involve teachers/educators, careers advisors, and parents. It can also include employers (or potential employers, disability service providers, and other community groups or individuals who may have a role in the lives of the young adults with an intellectual disability as they leave the school environment.

Historical overview of transition planning

Neubert (1997) contributes a comprehensive article describing past, present and future trends in curriculum and program development to prepare people with disabilities for **work** and for **adult roles in the community**. For the purposes of this review Neubert's work has been summarised in order to provide a brief historical overview of curriculum and programme development for people with an intellectual disability in the American context.

Before 1940: Early efforts to provide people with an intellectual disability with employment and life skills usually focused on instruction in areas including: manual arts; practical skills training; handiwork; and personal and social adjustment skills.

1940s and 1950s: Educators began to debate about curriculum and programme development for these students. In particular, educators debated whether the curriculum should be geared toward accommodating students in general education or whether the curriculum for students with an intellectual disability should focus on developing practical experiences associated with daily living.

1950-1960: Educators began to develop programmes which emphasised functional, vocational and social skills for students with an intellectual disability. As Neubert pointed out “although the terms have changed, the focus on persistent life functions continues today in curriculums – elementary and secondary – that prepares students for the transition from school to adult life” (p 7).

1960s: Recognition of the need to bridge the gap between school and work grew during the 1960s. Efforts to achieve this were referred to as work-study programmes. Components necessary in ensuring a position transition to adulthood were identified during this period as: vocational activity; sociocivic environment; self-concept or image as an adult. Most work-study programs included a prevocational curriculum, in school work experience, out of school work experience, and collaboration with vocational rehabilitation personnel. (This is not dissimilar to many secondary education programmes for students with an intellectual disability today.) Criticisms of early work-study programmes included that students were placed in unskilled jobs with little scope to gain additional skills and that both programme admission and content favoured males. It was recommended that the dignity of work and development of a positive self concept needed to be a focus of the curriculum and that teachers needed to focus on occupation specific skills and job placement for students with an intellectual disability. Finally, there were calls for research in the area of work-study programmes and more particularly, on the outcomes of such programmes. These criticisms and recommendations continue to have relevance in the current context.

1970s: The 1970s was a period of continued focus on occupational preparation and career development for people with disabilities. The preferred term used to describe preparation for work and adult roles in the community became career education. Career education, at this time, was a priority for all students. However, there was debate between special educators, who viewed career education as an extension of the occupational education and work-study movement of the 1960s, and general educators who saw career education as one aspect of the educational reform of the 1970s. Career education was seen as a way to reduce student dropout and to make education more relevant for all students. Work experience and some aspects of the earlier “persistent life skill” area were usually included in career education models during this time.

1980s: School-to-work transition issues were further highlighted during the 1980s as research identified poor post-secondary outcomes for young people with an intellectual disability. In 1987 ARC (Association for Retarded Citizens) identified what they described as “a severe gap in training and other kinds of services needed by young adults as they emerge from school” (ARC 1987). The goal and purpose of secondary special education again began to be questioned. Important themes in secondary level education

for students with an intellectual disability during the early 1980s were: individual transition planning; interagency agreements; varied vocational experiences; and the availability of a functional skills curriculum. The provision of transition services to secondary special education students was not compulsory during the 1980s. However, a number of state and local education systems developed transition models with staff designated to assume transition related tasks. Such tasks included efforts to increase students' vocational and community experiences. In many cases career education curriculums, employment skills curriculums; job experience and longitudinal vocational curriculums became available to students with an intellectual disability. Similarly to the 1970s, debate related to curricula content for students with an intellectual disability continued. Such debate was usually focused around the competing agendas of: minimum competency testing; increased academic requirements to obtain a high school diploma; the focus on school to work transition; the inclusion movement; and the supported employment movement. The content and curriculums of many secondary special education programs were again questioned and some researchers advocated a shift from academics to functional, vocational and independent living tasks for students with an intellectual disability in order to achieve an improvement in post secondary outcomes for this group (eg, Edgar 1987).

During this period the Supported Employment Movement also gained momentum. (Supported employment is explored in depth in the review "Work for adults with an intellectual disability").

1990s and the future: The transition movement and transition issues maintained prominence throughout the 1990s. The American legislation Individuals with an Intellectual Disability Education Act of 1990 (IDEA) represented the first time that federal legislation mandated that a statement relating to transition services be included in a student's individual education plan (IEP) by the age of sixteen. Student involvement in this process increased due to the fact that IDEA also mandated that student's transition goals be based on individual needs, preferences, and interests. A definition for transition included in IDEA broadened the concept of transition to include multiple post-secondary outcomes which, in order to be achieved, require educators to work carefully with both students and their families.

Neubert's (1997) historical overview of curriculum and programme development in the areas of preparedness for work and adult roles in the community illustrates that the concept of transition and transition planning is not new. While the transition movement has achieved prominence over the past 20 years, educators and others involved in the disability field have long recognised the need to explore ways of supporting young people with an intellectual disability to experience a positive adult life.

Why is transition planning important in the lives of young adults with an intellectual disability?

Transition is a process of changing from one state, activity or place to another. Although individuals and organisations may go through transitions during their lives, the transition of students with disabilities from school to life after school has emerged as a particularly crucial one, often affecting later participation rates in

employment and further education training, as well as quality of life (Riches 1996: p 71-2)

This statement goes some way to explaining the importance of transition and transition planning in the lives of young people with an intellectual disability. It is clear that the transition from education to adulthood for young people with an intellectual disability is fraught with difficulties (Tisdall 1994).

Lichtenstein and Nisbet (1992) commented that:

The process by which students with disabilities move from school programs to productive adult lives in their communities is undergoing intense scrutiny. For all young people, education and training serve as crucial stepping stones to becoming valued, contributing adults in society. However, historically, most students with disabilities have faced unrewarding prospects of unemployment, underemployment and long term dependency after their school programs end. These young adults face additional difficulties with other aspects of their community adjustment, including inappropriate living conditions, inadequate financial resources, restricted opportunity for post secondary education, limited opportunities for leisure activities and inadequate healthcare. The economic opportunity structure has been out of reach for this group so that their families, their communities and the students themselves have traditionally held low expectations (p 2).

At the end of the compulsory school period it is often assumed that young people with disabilities and their families will be able to find their way through a maze of different programmes, support and benefit schemes and different areas of responsibility. Fish (1987) contended that a lack of transition framework or agreed objectives makes continuity difficult and that new isolated initiatives only contribute to the confusion. Fish identified a number of questions required to be asked before adopting secondary and post school initiatives in order to ensure that additional barriers are not placed in the way of young people with an intellectual disability as they enter adulthood. Fish asserted a need for agreed transition related aims towards which all agencies can work. He also argued for a greater continuity over the three phases of transition, namely the final years of schooling, further education and training, and the early years of employment and independent living. Finally, Fish advocated for young adults with an intellectual disability themselves to be an integral part of the planning process in order to ensure transition related initiatives to be effective.

What do young adults with an intellectual disability have to say about transition?

Over the past 20 years disability researchers increasingly have emphasised the importance of giving a voice to people who have been labelled as having an intellectual disability. It has also been recognised that the development of high quality services and initiatives for people with an intellectual disability will only be achieved with the input from people with an intellectual disability themselves. In the area of transition planning there is a small (but growing) body of literature available which provides some insight into how

young people with an intellectual disability themselves view the process of transition and transition planning in their own lives.

Ryan (1997) explored transition and transition planning in the British context as part of a Values into Action initiative. The project was based on group and individual interviews with people with an intellectual disability, and/or their families and was developed in order to examine the impact of the 1993 Education Act which specified that Local Education Authorities in Britain were required to draw up transition plans for all students with special educational needs at the age of fourteen. This study explored student expectations, their experiences of the transition process, and the outcomes related to the transition phase that they had gone through.

Ryan's study is one of the few transition studies available which offers the perspectives of young people with an intellectual disability themselves. For this reason the findings of this study are presented here in detail. The young people who participated in this study reported a range of feelings when they were asked about leaving school. Their responses included:

I can not wait to leave school me, I'm gonna have a party.

I'm so-so about it you know. Part of me says I'm glad, but another part asks why.

I'll be glad to get out of this bedlam and away from the teachers.

It's frightening when you leave school. You get help from people, but when you've got to go into the big world, it's really frightening (p 6).

These responses make it clear that young adults with an intellectual disability (just like their peers without disabilities) display a range of feelings at the prospect of leaving school. When asked about the future, the participants in this study had clearly thought out aims and aspirations. Furthermore the young adults who took part in Ryan's study made the link between employment, earning money, and being able to achieve a more independent lifestyle.

I want to get a part-time job and go to college and do reading and writing.

I want to get a job, to save up all my money. Well at my age you get about, an allowance, about 56 pounds a week and then you just spend it on new clothes and trainers and that. But once you turn 18 you've gotta get furniture, pay the bills. So you've gotta save up all your money, get a job now, not later on.

I wanted to have a job as a hairdresser (p 6).

With regard to transition in housing some people were very keen and positive about moving out of the family home, while others felt ambivalent, or even very anxious at the thought of living away from their parents.

I want to get a flat on my own, but first I need to get a job because you have to pay rent and it all comes out of your wages.

I want to live near me mother, I want to be independent, to try and do it myself. I live with my mother at the moment, but I do want to move out ... go out and do things, see places.

You don't want to live in your mum's house for the rest of your life, you want your own house, your own job, you want to go out and do what you want and you don't want to have to rely on your parents (p 7).

Ryan's research also represents one of the few available studies that provide young adults' views of the transition planning process, and in particular the yearly review meetings that were intended to chart the progress of individual transition plans. Many of the young people were less than enthusiastic about transition planning meetings.

Terrible. All you hear about is what has happened to you this year and your parents are sat there listening. And this year has not been my very, very good year, do you know what I mean, I've had ups and downs (p 10).

Others were more positive about the value of such meetings.

I think it is good that you have all those meetings and things, cus you wanna say a lot out of your mouth and if you keep those things inside you, you're never gonna get a chance to do things. If on the last day of school, you leave and then you say 'right what's the next step', and you don't know what you're gonna do, that's no good. But if you have a meeting or you have interviews about certain things you get a chance to talk about it all. You let them know what you wanna do and they will try and help you out (p 10).

A number of participants in the study who had experienced exclusion from their own transition planning process in the past reflected on how the changes to the legislation (student involvement in transition planning was mandated by the legislation) had impacted on them.

Well at school I wasn't really allowed to go into my review meetings. It was my mum and dad and the head mistress and that. Which I didn't think was fair at the time really, you weren't allowed to go to them, you were left out. I really wanted to go in and tell them what I thought ... What I had in College, which was better, was that you could do your reviews and update, you know it was every six months or something. You were allowed to go in and see what everybody thought which was better really (p 11).

Most of the young adults and their families felt reasonably satisfied with the information and advice they had received throughout the process of transition planning. Advice and information was usually centred on the areas of further education, work and day provision, and curriculum/support needs required to pursue their chosen option. Interestingly, however, many of the young adults reported having difficulty with the method of presentation of information used during the process of transition planning.

I can read but not very well. If there is something with long words and words that are hard to understand then it's not easy (p 13).

I can't read much, I'm not very good. I seem to be better if people draw pictures. It's a lot better for people like me.

A common assumption regarding people with an intellectual disability is that they will find it easy to access information presented through a video. This medium was used by two of the colleges that provided post-secondary options for young adults with an intellectual disability. The following comment provides an assessment of how one young man found the video presentation.

It (video) can be helpful but it is not my ideal, ... I like people to come along and show me around the building. On the video they will say a lot of things, but they won't say what you want to ask them. So if you see them you can ask them and they will tell you, but you can't do that with a video (p 14).

These comments made by young people with an intellectual disability themselves regarding the accessibility of information reflect the findings of a recent New Zealand study in the area of health education and women with an intellectual disability (Mirfin-Veitch, Bray, Ross, Moore and Walker 2000). This study, which involved women with an intellectual disability themselves, identified a number of factors which impede the ability of such women to access health information and services. Significant among these factors was the mode of presentation used to impart health related information.

The participants in Ryan's study also highlighted the fact that transition planning should not focus exclusively on employment, college, or day service provision. Transition planning should be about the whole range of issues that affect young people as they approach adulthood including housing, benefits, and health.

I get advice on jobs yeah, but there is some other stuff I'm not quite sure about, I need to know more about council flats, I need to find out about that (p 14).

I need to know about benefits. I do really want to get a job, but I need more information to let me know about that (benefits). I need to find out about that (p 14).

This study also drew attention to some of the issues or problems that can accompany transition planning for students with an intellectual disability. One issue relates to the formal setting of transition planning meetings which can sometimes have the effect of silencing young people who may not have the confidence to say what they really think in such an environment. A consequence of this is that transition plans do not always reflect the wants and needs of the person they are intended to assist. Some of the professionals involved in transition planning believed this situation could be countered with the qualitative work that they conducted in the student's usual environment (eg, classroom). Another problem for young adults with an intellectual disability who are involved in transition planning is the frequency with which their preferred post-secondary options are not available to them. There is a significant dearth of vocational and non-vocational services for young adults with an intellectual disability as they leave school.

Ryan concluded that in order to ensure that transition planning is beneficial to young adults with an intellectual disability it must:

- be empowering; have an emphasis on real work
- be flexible
- focus on all aspects of personal development
- facilitate the development of local services.

Mitchell (1999) conducted a study which also provided some information relating to young adults' own perceptions of the process of leaving school and approaching adulthood. The study explored young people's educational or vocational movements after leaving school. It also explored the concept of a (more) independent adult status from the perspective of the study's young adult participants and their parents.

Data for the study were collected from 17 young adults and their families. At the time of participation the young adults were leaving five special schools over a period of two years. The decision to include only young adults who were leaving special schools was based on the author's view that special schools and the students who attend such schools are a peripheral and often ignored group within the education system. Interviews with young people with an intellectual disability, their parents and school professionals and other relevant professionals (eg, careers advisers) generated the data for the study.

This study showed that the experiences of further education and/or work were included into the school leavers' programmes at some point prior to leaving the special school environment. The young people who participated in this study generally felt positive about such experiences. Regular attendance at a mainstream college was seen by school professionals as an important way of easing the transition from special school. However, while this process was intended to provide the opportunity for young people with an intellectual disability to enhance their social networks, the young adults who participated in this study undertook college link courses but had little interaction with their non-disabled peers. Instead of being an inclusive experience, in reality their involvement in college continued to be separately organised and managed thus perpetuating the student's experiences of segregation.

This study also found that work experience was not an experience open to everyone who participated in this study. Socio-economic factors such as work placements available and/or the support that employers were able to offer to schools had implications for the availability of work experience for the young adults. However, it was also clear that attitudinal factors determined the work related opportunities that the young adults received. Mitchell found that almost half of the young adults with an intellectual disability that were interviewed during her study wanted to get a job after leaving school. Many of these young adults recognised that being a worker was part of being perceived as an adult and of adult life. School professionals who contributed to the study were more sceptical about the employment prospects of the young adults with an intellectual disability with whom they worked.

Mitchell wrote:

Indeed the opportunity structure that disabled young people faced was frequently mediated and interpreted by professional assessments and judgements of what was regarded as feasible or just being realistic. Consequently, these perceptions, including taken for granted ideas about appropriateness helped to stratify and differentiate the opportunity structure to which school leavers were orientated (p 757-8).

Mitchell concluded that her research demonstrates that the issues surrounding work and employment are complex. Particularly difficult is the dichotomy between the aspirations that young people (and in many cases their parents) hold regarding employment and the fact that real employment opportunities remain scarce for this group of young people. Mitchell contends that a broader interpretation of work and employment is imperative to the task of creating greater employment opportunities for young people with an intellectual disability. (A more comprehensive discussion of work and employment is contained in a later review on Work for adults with an intellectual disability.

Thoma, Rogan and Baker (2001) conducted a qualitative study involving eight students with moderate, severe or multiple disabilities. The study focused on the students' involvement in transition planning during their final year in high school. Participant observation, in-depth interviews, and document analysis were data collection methods used to carry out this study. The students who participated could all communicate preferences and interests.

Thoma et al reported that students with an intellectual disability were not involved in preparing for transition meetings and often did not know when transition meetings were scheduled. All students were physically present at formal transition IEP meetings but had no designated role within the process. School personnel determined the content of the meetings and controlled them, interacting almost exclusively with parents while doing so. The adults involved in the meetings were found to speak about rather than with students and frequently focused on student deficits.

Thoma et al found that while the adults involved in the transition planning described it as being positive, the outcomes that were achieved were found to have little or no connection to student goals. Kathy, a student participant in the study articulated some of her frustration at the transition planning process:

I just want to say that being disabled isn't easy, especially at the age of eighteen. It's basically hard because you want to do something in life and sometimes people won't let you... (p 25-6).

Thoma et al concluded that the definition of successful transition must include outcomes that match student preferences, interests and dreams for the future. Transition goals and outcomes are often based on others' perceptions of the likelihood that they will be achieved rather than on student choice. As a result, Thoma et al advocate for further research to understand the impact of student centred, student directed planning on actual outcomes.

Families' perspectives on transition

In a review of Relationships for adults with an intellectual disability (Mirfin-Veitch 2001) the role and influence of families in the lives of this group was discussed.

It is also widely acknowledged that families play an active role in making decisions which affect the lives of adults. Men and women with intellectual disabilities often continue to seek decision making support from their families into

adulthood. It is also common for adults with intellectual disabilities to accept families' input, (or feel unable to prevent) their families from making decisions without considering their views on specific issues. Families influence, or make decisions about: where adults live; who supports them; with whom they develop relationships; how they spend their leisure time; and where they work. This makes it important to examine the relationships that exist between adults and their families. The nature of these relationships have a critical influence over the level of independence and quality of life adults with intellectual disabilities are able to achieve (p 5).

This statement continues to have resonance when applied to the area of transition and transition planning for young adults with an intellectual disability. Families play a pivotal role in the lives of people with an intellectual disability. Families usually remain the primary 'service coordinators' for their sons and daughters, even after they have left school.

As young adults with an intellectual disability make the transitions from student roles into adult roles their families must also make related transitions (Thorin and Irvin 1992). Horrocks (1994) suggests that as the people who (often) know their son or daughter best parents need to be an integral part of the transition planning process. As a consequence, there is a significant body of empirical research which explores parents views of the transition related experiences of their young relatives with an intellectual disability.

In a qualitative study of parents' perspectives and needs during their child's transition from school to adult life Hanley-Maxwell, Whitney-Thomas and Pogoloff (1995) found that parents of students involved in the transition process usually have a vision for the future of their child. An example of a future vision is shared by a parent of a young women with a disability about to leave high school.

I have always pictured her in a group home of 5 or 6 or 7 people... I would picture that she would spend holidays at home, and perhaps some weekends at home. I would like to see that. Her spending weekdays getting adjusted to work and weekends, not all of them, here to do something with family. I do hope that she will have more independent time, and that she will develop some activities and friendships that would move into those weekends and quality time... I will always want to watch and make sure that she is not being taken advantage of, getting to work on time, getting to do her leisure activities... I do want her to have the experience of not living at home... I hope to have more family picnics and gatherings and stuff, but I picture other people besides family doing that (p 6-7).

Hanley-Maxwell et al interpret the findings of their study as illustrating that parents do not see transition as simply a period of school to work, instead it is seen as a major family event that signifies a total life change for all concerned. Parents involved in this study were concerned with a number of factors as they moved into the transition and transition planning phase alongside their young adult sons and daughters. These factors were described by Hanley-Maxwell et al as: residential visions; social visions; and free-time visions. Parents perceived that the achievement these positive visions for adult life was dependent upon collaboration between education services and adult services. Parents in this study identified barriers to transition as being waiting lists for adult services, and

perhaps more importantly, the lack of social networks that often characterised the lives of their children with an intellectual disability.

Whitney-Thomas and Hanley-Maxwell (1996) further explored this area through a study which involved parents of young people with and without disabilities as they prepared to leave high school. Parental views were sought through a questionnaire which incorporated questions relating to parents': comfort with the transition; vision for the future; and response to the schooling process. The findings suggested that parents of students with disabilities experience greater discomfort with the transition process from school to adult life than other parents, and have less optimism about their son or daughter's future. Similarly to the findings presented in the previous study (Hanley-Maxwell et al 1995) this study confirmed that families are also affected by the transition process and that parents experience particular difficulty during this process. It also highlighted the pivotal role that families perceive that school personnel are required to play in order to achieve the successful transition from school to adult life of young people with an intellectual disability.

Ryan (1997) explored parents' views of the transition to adulthood of their sons and daughters with an intellectual disability. Many parents were aware of, and concerned about a serious lack of post-school options for their family members. For this reason their hopes and aspirations were often pragmatic and focused, for example, on gaining and maintaining a place for their relative within the available adult services. Parents' needs as care providers often determined the configuration of services or employment opportunities that young adults were able to access. This point is illustrated by the comment made by a parent:

They said that they would have her at (day centre). We would be happy with her going to college two days and three days and (day centre), do you know what I mean 'cus we need to go shopping, well it takes ages anyway, and you can't go shopping when you've got Sarah... We can't have her at home (p 8).

Some families commented on the impact of paid employment for their sons and daughters on the family finances.

We have been told that if Tim gets a full time job and he enjoys it, and let's say he does it for a year or two years and gets paid 100 pounds per week, we lose his benefits, Now, if you're on a tight income you can't afford to lose benefits...(p 8).

Other families recognised the long term nature of the transition years and held their own aspirations regarding their sons' and daughters' futures. One parent said:

At the moment it is safety first. We will play it safe for a while but he is showing us that he is very capable. I think eventually it would be great for him to have a part-time job, as a van driver's assistant or something like that (p 9).

Another parent commented:

We want her to have a life that gives her the greatest opportunities that she can have. To be herself and to be with people she is comfortable with is most important (p 9).

Finally, Ryan found that both parents and the young people with an intellectual disability themselves highlighted consistently the issue of limited post-school options concluding that involvement in transition planning is meaningless if there are no options, services or support at the end of the process. The following comment was made by a parent.

They were listening to what I was saying and could obviously empathise with the situation we were in, but couldn't come up with an answer because there wasn't one (p 27).

Jennie Lancaster (1997) provides a personal perspective on the transition to adulthood for young people with an intellectual disability. The parent of three young adults with an intellectual disability herself, Lancaster suggests some strategies for assisting with the transition from education to adulthood for this group of young people.

Planning ahead, looking at different options, and listening to your child are all important elements of helping your child with special needs move to adulthood (p 26).

Lehman and Baker (1995) explored mothers' expectations for their adult children in the areas of future living arrangements, employment/education goals, and social relationships. The views of mothers of adolescents with severe disabilities were contrasted with those of mothers of non-labelled adolescents. Forty mothers participated in qualitative interviews for the purposes of the study.

Lehman and Baker found that both groups of mothers shared similar expectations for their children. Most significantly, both groups of mothers hoped that their children would achieve independence from the family. However, independence was defined differently by the two groups. Mothers of non-labelled youth indicated the independence of their children by being less able to articulate the specifics of their children's futures. In contrast, mothers of youth with an intellectual disability described a future that included support services. Furthermore, another interesting finding was that in contrast to mothers of non-labelled youth (who expected that their children would move from the family home once they had established financial security) mothers of young people with an intellectual disability expected their children to move away from home as soon as they had completed high school. Lehman and Baker suggested that this difference may be related to fatigue caused by the increased demands of raising a child with a disability.

A number of researchers have investigated the issue of parental stress during the period of transition from education to adult life for young people with an intellectual disability. Thorin and Irvin (1992) collected data from 42 members of families of young adults with severe developmental disabilities and identified the following issues as those most stressful for families: the availability and quality of adult services; interactions with adult services; family financial problems and disagreements. This final point illustrates the fact that not all stress present within families including a person with a disability should be attributed to issues of disability.

Canadian researchers Mellon, Wilgosh, McDonald and Baine (1993) conducted in-depth, qualitative interviews with 12 parents to identify the types of stresses that older adolescents or young adults with severe disabilities experienced during transition. The six

themes that emerged as most significant in this study related to: uncertainty about the future; transition in services and a lack of choices or options; advocacy; physical maturity; and individual vulnerability.

Similarly, Thorin, Yovanoff and Irvin (1996) administered a survey that was designed to determine potential dilemmas of most significance for families involved in young adults' transitions to adulthood. This study very effectively highlights the ambivalence or conflicting emotions that many families of young people with an intellectual disability can feel during this time. Thorin et al presented the following dilemmas as being identified during this time as a result of their study:

- wanting to create opportunities for independence for the young adults and wanting to assure that health and safety needs are met
- wanting a life separate from the young person and wanting to do whatever is necessary to ensure a good life for him or her
- wanting to provide stability and predictability in family life and wanting to meet the changing needs of young adult and family
- wanting to create a separate social life for the young adult and wanting to have less involvement in his or her life
- wanting to avoid burn-out and wanting to do everything possible for the young adults
- wanting to maximize the young adult's growth and potential and wanting to accept the young adult as he or she is

The critical role of parents (and other family members) in decision making and planning in the lives of young men and women with an intellectual disability is crucial to both educational and post-school success (Lichtenstein and Nisbet 1992).

In a study of prediction of student participation in transition-related actions Spencer and Sands (1999) discussed the role of family in this process. The study was designed to identify student and environmental variables that predict active, self-determined student participation in the transition process. Specifically, the study sought to identify (a) student participation in planning related to transition goals (b) student follow through or action-taking based on plans (c) student self-evaluation and regulation of behaviours or thinking based on progress towards targeted transition goals.

The study was successful in identifying a combination of school, student and family variables that appeared to be predictors of student participation in transition related actions. With regard to the issue of family variables, the study showed that students who had a family environment that was not particularly controlling or overly rule bound were more likely to demonstrate self-determined participation in transition actions. Spencer and Sands contended that educators and other professionals involved in transition planning and/or services should focus on encouraging parents and families to involve their family members with an intellectual disability in decision-making regarding their own future. Furthermore, Spencer and Sands acknowledged that such a process would require parents and families to allow students to gradually assume increased levels of responsibility for themselves. This process involves parents relinquishing some control and supporting their young adult sons and daughters in this new "risk taking" role.

The fact that many parents have a great deal of difficulty in coming to terms with their sons' and daughters' with an intellectual disability approach toward adulthood is confirmed by the findings of Mitchell's (1999) research. The expansion of further education (FE) options for young adults with an intellectual disability was embraced by parents. Parents expressed a sense of relief that their sons and daughters had post school options to move on to. Some parents even stated that they wanted their son or daughter to stay in education for as long as possible to delay the transition to other adult settings. For this reason it is not surprising that 94 percent of the young adults who participated in this study were engaged in some form of education either full or part-time (school, college or continuing education). Some parents in this study also recognised the need "to look beyond narrow interpretations of employment to broader ideas about meaningful daytime occupations".

Joanne den Otter (1994) raised a number of issues related to post-school options for people with an intellectual disability. Den Otter's paper outlined the effort of the parents for Post Secondary Options Group. This South Australian group was formed in 1992 by a number of parents/carers whose sons and daughters with an intellectual disability had left school, or would soon be doing so. The Parents for Post Secondary Options Group held a forum at which it was decided that an issues paper should be produced that would highlight the most significant issues faced by parents, families and carers, and that would offer suitable solutions to those problems.

Parents identified several problem areas common to current transition initiatives. In particular they asserted that: people with severe intellectual disability are largely excluded from employment or training options because of an enduring assumption that this group of people have no need for such opportunities; the stress and strain on family carers is exacerbated by a lack of quality post-school options for young adults with an intellectual disability; and that while respite services continue to fail to meet the needs of many families (and people with an intellectual disability themselves) the demand for such services would be reduced if quality post-school options were available.

This group concluded that a post-school options program would provide people with an intellectual disability day options in the form of employment, training, life skills, recreation, or a combination of these. To be effective, such a programme would need to offer:

- an individualised service tailored to individuals so that maximum benefit is gained for both client and carer
- on-going support – program would be a long term, permanent option with on-going support and recurrent funding
- choices and flexibility
- collaboration between planning bodies, funding bodies and service delivery agencies to ensure clients do not fall between the gaps
- transition – a program which begins at secondary school to plan for transition from school to adult life
- communication – inclusion of manual communication (signing) in the school curriculum for all students would ensure wider opportunities for communication for non verbal students
- a focus on young people with a severe disability

- consideration of issues associated with incontinence (supported options must address incontinence and train staff accordingly)
- country services (specific attention needs to be given to the inclusion of country regions)

Many of these components have been included within recent or current transition projects as described later in this review.

What do educators and careers advisors have to say about transition and transition planning?

Information relating to educators' and careers advisors' views of transition is focused most frequently on issues associated with employment. This heavy focus on employment indicates that transition planning often fails to incorporate consideration of other factors that may impact on the lives of young people with an intellectual disability as they approach adulthood.

Morgan, Moore, McSelwyn and Salzberg (1992) surveyed 104 secondary educators to ascertain what activities these professionals considered important in transition planning. Findings indicated that secondary special educators considered that teaching social skills and job skills, involving parents in transition planning, and matching student's skills to jobs were the transition related activities that they perceived to be most important. Differences were found in the importance of some activities for students with mild disabilities versus those labelled as having severe disabilities. For example, interagency collaboration was perceived as being more critical for students with a severe intellectual disability. Morgan et al interpreted this finding as being linked to the involvement of a greater number of professionals from a range of different areas in this group of students' lives. Transportation and case management was also considered more important for students with a severe intellectual disability. These findings highlight the critical need to consider the issue of transition and transition planning for young people with a severe intellectual disability.

A study by Armstrong and Davies (1995) which focused on the experiences of 29 young people about to leave special education also provided some insights into how educators and career professionals view transition from education to employment. Findings generated through the study suggested that although the quality of advice and support offered to young people at schools was good, there was a subsequent lack of coherence which can make these school leavers highly vulnerable when they move to employment, training or further education.

The study focused on school leavers who were attending special schools specialising in the education of children and young adults with a moderate intellectual disability and /or emotional difficulties. Nine of the students involved in the study had an intellectual disability. Interviews were conducted with the young people themselves, with teachers in each participating school (total 6) with responsibility for careers advice, and with specialist advisors from the careers service of the six schools. The interviews focused on a number of key questions including: What are the main characteristics of the occupational aspirations of the leavers in the sample? What main assets/opportunities do these students have in assisting them to achieve their aspirations? What are the main

barriers they might face? What type of careers/employment advice do the students want/need, what do they receive? What systems of support were perceived to underpin the vocational advice the students received from their teachers and careers advisors?

This study generated a number of important findings which highlight the contrasts between students' career aspirations and the views of the education and career professionals whose job it is to support them to achieve their goals. The students who participated in this study had clear occupational aspirations – all but two students were able to name an occupational area they were interested in. Many of the students were able to describe strategies that they had or would put in place in order to achieve these aspirations. The interviews with the teachers and careers advisors generally confirmed that the students' aspirations were realistic. However, subsequent discussions with these individuals indicated the complexity of the issues related to the students' occupational aspirations. For example, while a student's career goal might be realistic in terms of their ability, it was in many cases unrealistic in terms of competition within their chosen employment areas. Furthermore, teachers and careers advisors agreed that an application from a candidate who had received special school education would be perceived less favourably than a candidate from a mainstream setting. In summary, teachers and careers advisors were more skeptical than the students about the likelihood of them later realising their career choices.

A statement made by a careers advisor who took part in this study reflected on the different experiences of students with moderate learning disabilities (mld) as opposed to those with emotional and behavioural difficulties (ebd).

The destinations of mld are very different to ebd leavers. It is very rare for ebd leavers to go to college. By and large they are anti youth training. The main factor against youth training is the lack of money. A lot of ebd youngsters who do enter youth training do not stick at it because of its rigidity. Mld youngsters tend to settle better into youth training; they are more prepared to follow the rules (p 72).

In contrast to this perspective however, another careers advisor had a different perspective on this issue and cautioned against prescribing rules. She had noticed increased interest in further education by both groups of students.

Teachers and careers advisors believed that students in the special education system received the benefit of a much higher level of individual support in relation to careers advice. Also beneficial was the fact that this support was available both prior to and after leaving school. Furthermore, teachers and careers advisors perceived leavers from special schools had access to specialist provision developing within youth training and further education services which were tailored to meet their special needs. These views were shared to some extent by the students, however over half of the participating students believed their chances of success were dependent on their own personality and determination to succeed.

Ryan (1997) illustrated the difficult position that educators and other professionals involved in transition planning frequently find themselves in.

We would like to help the students here to achieve A,B, or C, but what you end up doing is channeling the needs and wishes into a few options. You end up trying to fit all sorts of different pegs into similar holes (p 23).

Gallivan-Fenlon (1994) included service provider perspectives as part of a wider qualitative study of school to adult life for young adults with disabilities. Gallivan-Fenlon's study provides further information relating to the experiences and views of school personnel and other adults involved in the transition process. It was found that school personnel and adult service providers were likely to hold more restrictive expectation of employment, community living and community participation than young adults did themselves. Adult service providers highlighted the need for school personnel to initiate transition planning to ensure that student's and their families were more likely to receive greater choice in terms of post-school options. Finally, a worrying finding was that school personnel frequently reported their own lack of experience or expertise in the area of transition planning. A particular issue was the fact that school personnel often had little or no knowledge of available adult services. Such a situation is a significant barrier to successful transition planning.

Kueneman and Freeze (1997) also conducted a study which compared and contrasted parents' and teachers' perceptions of the transition planning process. The parents and teachers involved in this study had participated in the specific planning process PATH (Planning Alternative Tomorrows with Hope). PATH is a eight step transition planning initiative which maintains the student with a disability as the central figure of the process.

Kueneman and Freeze found that both parents' and teachers' perceived the PATH process to be effective, and felt that the active involvement and reciprocity of communication that were part of this process to be beneficial to all concerned. A point of difference in parents' and teachers' views could sometimes be seen in the area of goal setting. Some teachers' felt that parents had unrealistic goals for their son or daughter's future. This finding is reflected in other studies reported here which indicate that some school and/or adult service personnel have a restricted view of what students with an intellectual disability will be able to achieve in adulthood.

Transition projects

Before commencing this section it is important to note that the majority of projects described as being focused on transition usually concentrate on the issue of employment. This weighting toward employment is reflected in the topic of Transition Projects presented here. McDonnell, Hardman and Hightower (1989) articulate the significance of employment and, consequently, the importance of creating ways to increase employment opportunities for young adults with an intellectual disability.

Employment is a critical aspect of successful adult life and a prerequisite for full acceptance in society. Employment influences our status and quality of life within the community. Those who work are perceived as contributors.

Those who do not are often viewed as liabilities. People with severe handicaps generally fall into the latter category not because they are incapable of work but because policy makers and disability professionals have been more oriented to 'serving' these individuals than creating opportunities for employment (p 396).

Research evidence suggests that both school and community resources affect the transition of special education students from high school to work, post secondary education and other outcomes. Transition programmes have been identified as falling into two categories, traditional in-school programmes and newer transition oriented services (Fairweather, Stearns and Wagner 1989). Traditional in-school preparation programmes are likely to include vocational education, support services such as counselling and occupational therapy and opportunities for mainstreaming with peers. Non traditional transition services include: having a programme designed specifically to assist special education students with the transition to employment and post secondary education; developing close ties between secondary schools and service agencies; and providing job placement services. Community resources have also been found to be related to the achievement of successful transition. These include adult services, vocational counselling and training, and the availability of employment opportunities after exiting special education.

Riches (1996) reported on a transition initiative which commenced in New South Wales (NSW) in 1989. The NSW Project had the aim of assisting students with disabilities to make the transition from secondary educational settings to community living and adult life roles. This project was funded by the Special Education Plan of the NSW Department of School Education and provided an opportunity to introduce and evaluate a system that would meet the transition related needs of students with disabilities in both special and mainstream secondary education settings. Most students who were included in this project were students who had an intellectual disability.

The transition model used in this action research project acknowledged that transition does not just relate to employment. Other areas are important to achieving meaningful school to adult life transitions and as a result the following areas were included in planning for the project: post-compulsory education and training; employment; financial security; residential arrangements; individual competence in community living; recreation and leisure; and quality of life issues such as friendships, satisfaction and choice. This project was also based on the premise that transition is a **process** not a programme therefore the aim was to establish a means by which young people with disabilities could access a range of opportunities and options which met their individual needs. As a result, the NSW Project involved collaborative teams which operated at the individual, school, community, and central planning and policy levels.

The longitudinal nature of the NSW transition project, and the evaluation that took place as an integral part of the project resulted in a number of key findings. Critical features to ensuring an effective transition for students with disabilities were identified in this project as:

- *commitment and support at the central policy and funding level;*
- *development and implementation of individual transition planning, involving students, parents/caregivers, advocates, teachers and community agency personnel responsible for providing services;*
- *the provision of relevant and appropriate school curricula and instruction;*
- *access to and provision of appropriate adult services, including meaningful training and employment options post-school;*

- *liaison with and linkages of students to post-school options prior to leaving school;*
- *on-going professional development;*
- *community involvement and local planning; and*
- *interagency cooperation and collaboration at all levels (p 74).*

Riches highlights the essential role of whole life planning during the transition year and stresses the importance of collaboration between the range of services and service providers to young adults with an intellectual disability, not merely those with an employment focus. In Riches' view, to concentrate solely on the issue of employment fails to address the needs of students with disabilities who wish to transition into further education or non-vocational options. The current environment relating to further education (adult education) is explored later in this review.

Dobson and Jay (2000) describe the efforts of the CREDO Project (Creating Real and Equal Development Opportunities) which aims to develop good practice and planning with young people described as having profound and complex impairments as they look forward to adulthood. The CREDO Project aims specifically to diminish instances of exclusion and challenge in order to make a practical impact on the lives of young people with an intellectual disability. The CREDO Project is the result of a grant from the National Lottery Charities Board in Britain. In real terms, the CREDO Project uses the strategy of person-centred planning with young people (13-19 years) in England and Northern Ireland. It particularly focuses on the issues faced by individuals and those who support them.

The objective of the CREDO Project is to be part of a process that allows the young person and their family to prepare a plan or simply to talk about concerns. The young person with a disability remains at the centre of this process. Three main areas of work the project will deliver have been identified: planning with young people with profound and complex impairments; developing circles of support; and sharing models of good practice.

Taking time to get to know a young person and to begin to plan for the future in an environment that is known and friendly will empower the individual to challenge existing prejudices and low expectations of disabled people (p 19).

The description of the project contained in this article fails to address the complex challenges and issues associated with accessing the goals and common aspirations of young people with high support needs. In particular the practical challenges of implementing a person-centred planning approach with young adults with severe disabilities and communication difficulties are not addressed.

Florian, Dee, Byers and Maudsley (2000) provide greater information in this area. Florian et al report on a survey of provision for students with profound and complex needs aged 14 and over, in England and Wales. The survey is part of the Enhancing the Quality of Life (EQoL) project which has the aim of constructing a framework for learning which will support improvements in quality of life for this group of young people.

The EQoL Project involves three phases, the first phase is reported here. Phase One involved the administering of a national survey which was designed to establish a better

understanding of the characteristics of provision of support for people with a profound and complex intellectual disability. The purpose of this was to increase awareness of issues relating to this group and to identify the support necessary to facilitate the transition from adolescence to adulthood. The questionnaire was sent to all secondary and all-age special schools for students with an intellectual disability. The questionnaire sought information relating to students with a profound and complex intellectual disability. For the purpose of this study profound and complex intellectual disability was defined as: a profound cognitive impairment or learning difficulty; and a complex aggregation of difficulties in more than one area of life. The questionnaire data allowed the researchers to conduct a mapping exercise whereby the transition related activities or destinations were identified.

The results of this study confirmed the widely held view that students with profound and complex learning difficulties have few opportunities to participate in community life as adults. For example, 39 percent of the students in the study aged 19 or older remained in the school environment rather than making the transition to other post-school options. Young adults with a profound and complex disability (outside the secondary school environment) are severely under-represented in further education. Florian et al asserted that:

... despite the efforts by school staff to find alternative provision, the reality for many of these young people is that they remain in the same setting, often in school, interacting with the same people year after year with little opportunity for change (p 127).

Florian et al assert that without meaningful choices and alternatives, the promise of social inclusion cannot be realised. Phase Two of the EQoL Project will, as a result, focus on working with practitioners to develop a curriculum framework and materials which will help to facilitate transition for students with profound and complex disabilities.

Concerns about the lack of availability of transition services for young adults with an intellectual disability are consistently highlighted in the research literature. Baumeister and Morris (1992) describe a vocational education model delivered in rural Western South Dakota. The Black Hills Special Services Cooperative (BHSSC) has responded to the identified need to develop and improve vocational education options for students with educational or economic disadvantages or disabilities. This initiative was developed in response to the fact that while only 40 percent of South Dakota's secondary population went on to post-secondary schools, graduation requirements and the curriculum focused in preparation for college. The BHSSC now provides a range of vocational education services which have both itinerant and centre based components.

The range of services provided include more traditional approaches of evaluation, curriculum development and vocational instruction , as well as creative approaches including entrepreneurial pursuits and community economic development. Implementation of this mix of approaches was found to be necessary in order to be able to deliver a range of services to young adults in this rural area.

Donovan (1998) also describes a transition project which includes a community focus. The Bridges Project (funded by the Marriott Foundation) is a transitional program that places final year high school students in work experience 'internships'. The project was

designed to address the fact that most young people with disabilities who exit the education have little or no work experience. The criterion for acceptance into the Bridges Project is that students indicate a willingness and commitment to work. Once a student selected to be part of the project they begin orientation and training. Workshops do not simply focus on vocational skills but also encompass life skills training. Students are encouraged and supported to talk about the kinds of jobs they would like to do and it is this information that facilitates the process of matching students to employment opportunities. The Bridges programme also provides training to employers in recognition that a successful work experience placement is dependent on both employers and employees.

This type of approach to transition planning in the area of employment is supported by research. A study of employment preparation for students with a severe intellectual disability (McDonnell, Hardman and Hightower 1989) highlighted the importance of implementing a cooperative model of employment preparation. McDonnell et al contend that while employment programs should be designed to ensure that there is access to jobs that are consistent with both the capabilities and vocational interests of the individual students, vocational training should also focus directly on the employment opportunities available within the local community. This process requires the collaboration between schools and employers as seen in the bridges project.

Knight and Aucoin (1999) also discuss the issue of on the job training for students with an intellectual disability. Research has shown that students who have received work experience as part of their high school vocational education programmes are more likely to maintain competitive jobs. Work experience or on-the-job training provides students with an intellectual disability four main benefits: an authentic context for applying problem solving skills; avenues for exploring a range of careers; appreciation for the connection between employment and learning; and opportunities for networking.

Knight and Aucoin contend that both formative and summative assessments are essential to achieving a successful transition from education to employment. Data collected for the assessments should reflect student, teacher, and employer views. Knight and Aucoin have developed a 28-item inventory which is intended to assess for 'job readiness'. The inventory includes three components: life skills; affective skills; and employability skills. The inventory is designed to be administered immediately prior commencing, and directly following the completion of a student's work placement experience.

After trialling the inventory Knight and Aucoin reported a number of benefits. Employers felt that they gained a more comprehensive understanding of the work experience and felt part of the educational team by being asked to participate in the assessment. The work experience coordinator or 'job coach' reported that using the inventory facilitated an opportunity to share decision making regarding how a work placement actually went with another adult (ie, the employer). Interestingly, when the students were questioned about their perceptions of the inventory a common response was that they became "more aware of what they were not able to do and more aware of what they should be able to do." While Knight and Aucoin do not explore this finding any further, the students' comments could be interpreted as suggesting that completing the inventory did not represent a particularly positive experience to them. As was reported in a study referred to earlier in this review (Ryan 1997), transition planning does not represent a positive process for students if their deficits, rather than their achievements and skills, are emphasised.

The time required to complete, score and report on the assessments was seen as a challenge to frequent use of the inventory. Another problem highlighted by both educators and employers was that in some cases they had little opportunity for observing skills, or for providing assistance to learn new skills, therefore assessments of mastery were questionable.

Patton, de la Garza and Harmon (1997) describe a California programme titled Project WORK. The project is based on the premise that the transition to employment is dependent on adult agency referral, family support and involvement, employability skills training, and on-the-job support. Project WORK is a classroom-based programme that is designed to place students in jobs within six weeks. The commitment to obtaining a job placement in the tight timeframe of six weeks is based on an underlying assumption that students cannot learn and apply the classroom material without concurrent real life work experience. In other words, the project described by Patton et al does not ascribe to the notion of 'job readiness'. Also included in the Project WORK curriculum is self advocacy training to ensure that students can become active participants in the adult agency referral process, and they are given advice and training in how to involve their families in employment goals.

Stolting (1998) also explores vocational training as provided by a Tennessee based organisation, The Orange Grove Centre. This organisation has the goal of providing adequate training for students so that they can gain employment in the community. Students with an intellectual disability are selected by a teacher (rather than being self referred) and then undergo a series of assessments which facilitate the development of an Individual Written Rehabilitation Plan (IWRP). The IWRP is intended to identify what kind of program would suit the student's needs. The student is then assigned to Work Adjustment Training, a state funded vocational program that provides supervised job training for a maximum period of sixty days. At the end of the program the students are evaluated *and if the staff feel they are ready for employment* they will then begin the process of contacting community employers. The Tennessee Project presents a sharp contrast to the California project previously described which recognises that many students with an intellectual disability need to experience a real employment setting in order to be able to apply the skills learnt in the classroom environment.

A paper by Halpern (1989) provides an alternative to the focus on employment as the most important transition goal. Halpern contends that the transition movement, transition planning, and the outcomes of transition must be more broadly conceived than simply employment. Halpern suggests that community adjustment should be the desired outcome of transition planning and transition services. Within the broad category of community adjustment there are three distinct components (according to Halpern): occupation; residential adjustment; and the existence of desirable social and interpersonal networks. Furthermore, Halpern suggests that these three societal dimensions must be augmented with personal dimensions such as satisfaction, self-esteem, and empowerment. It is interesting to note that in a review of the literature conducted for the purposes of this paper Halpern found that personal satisfaction was determined by the existence of social networks (rather than by employment). This finding reiterates the need for transition planning to focus on all aspects of a young person's life, not simply on employment.

A recent paper provides information regarding the transition from secondary school to alternative post-secondary options. Moon, Grigal and Neubert (2001) point out that in

contrast to other young people who typically leave school at the age of 17 or 18, young people with an intellectual disability stay in the high school setting until they are 21 years old. Increasingly, parents and educators have asserted a need for alternative opportunities for older students in more age appropriate settings such as colleges or businesses.

Moon et al discuss the Maryland On-Campus Outreach Project which is designed to provide technical assistance to individuals or institutions providing post-secondary options for young adults with an intellectual disability. Moon et al state that the overall goal of post-secondary options for young adults is to provide students with new educational environments which raise the standard of expectation to one more similar to that of young adults in general. While programmes of this kind have a range of specific goals which are closely related to typical transition projects, they occur in an environment that is typical for young adults who are post-secondary age.

Transition outcomes

Many transition related studies are conducted within the specific environment of special schools. Sax, Noyes and Fisher (2001), however, compare the outcomes for students with significant disabilities leaving public schools who experienced both 'inclusive education' and a 'seamless transition', with a similar group of young people who did not. Sax et al define 'inclusive education' as meaning that students attend their local school with their age and grade peers in the general classroom (with appropriate support). 'Seamless transition' is a term used to describe the use of resources from school and post school systems to share costs associated with supporting a student driven approach to choice making and transition planning.

The study involved 33 students with significant disabilities, six of whom had received inclusive education and a seamless transition (according to the criteria used in the study). Sax et al reported that the students who had received inclusive education and a seamless transition entered their adult lives well situated for success. Most importantly, these students did not receive a disruption in services after leaving high school. The comparison group of students received a great deal of disruption and often did not have an adult service option available upon leaving school. Employment options were also more favourable for the smaller group of students who (two months after leaving school) received higher wages and worked a greater number of hours per week.

Sax et al contend that these findings support the positive benefits of inclusive education and suggest that students with an intellectual disability acquired skills necessary for adult life quite naturally in this setting. They also believe that the seamless delivery model provided students and their families with time to evaluate the appropriateness of adult services. This minimised disruption when transition from school finally occurred.

Hughes, Eisenman, Hwang, Kim, Killian and Scott (1997) conducted a literature and analysis of measures of educational outcomes for students with disabilities involved in secondary level education. Hughes et al contended that the American public has become increasingly concerned with educational outcomes for all students due to the dissemination of a number of reports which have indicated that the results of schooling for many American students are mediocre to poor. This national concern with educational outcomes extends to students with disabilities for whom unemployment, economic

dependence and segregation are the future for many students as they leave high school and enter adult life (Hughes et al 1997). Identifying and analysing educational outcomes are important according to Hughes et al because it can (a) inform researchers, practitioners and policy makers regarding the scope and impact of educational programming and (b) suggest areas in educational curricula in need of attention or improvement.

Hughes et al contended that despite long term support of a comprehensive community based, functional curriculum for students with disabilities, no attempt has been made to establish whether this broad based curriculum is actually being targeted in intervention research. The purpose of their study therefore was to (a) propose a consensus list of secondary special education student outcome measures to serve as a conceptual framework for reviewing the literature and (b) to analyse the empirical literature to establish a knowledge base of aggregate student outcome measures targeted in intervention research and investigated on the individual student level.

A conceptual framework of educational outcomes was developed. The categories of educational outcome identified by Hughes et al (1997) were employment; social interaction; community adjustment, competence and community living; psychological wellbeing and personal satisfaction; personal development and fulfilment; recreation and leisure; social acceptance, social status and ecological fit; self determination, autonomy and personal choice; physical and material wellbeing; individual and social demographic indicators; and civic responsibility and activity.

Three major findings of the study were reported by Hughes et al to be the increasing trend toward (a) targeting a broader scope of student and adult outcomes (b) involving persons with disabilities as active participants in their educational programmes and (c) incorporating the opinions of participants, teachers and important others into the evaluation of program goals and outcomes. Hughes et al outlined the following recommendations for future research, practice and policy development based on their findings.

- The focus of applied research must be expanded. Unless all aspects of a person's life are addressed by educational efforts we should not expect to see a new generation of high school students who are involved in supportive and intimate relationships, maintaining their own homes, experiencing personal satisfaction, making and acting responsibly on personal choices and decisions, advocating for themselves, engaged in meaningful employment or other daily activities.
- Programming efforts must start earlier in students' lives. Hughes et al found that interventionists are waiting until students are out of school or ready to exit school before introducing transition planning efforts. Early intervention transition programming may relate to more positive outcomes for students as they enter their adult lives.
- Direct observation of outcomes must be supported by input from students. Direct observation was used in 96 percent of the reviewed studies to assess the effects of interventions on outcome measures. However very few studies reported the input of students regarding their own goals in their educational programs. Findings of

direct observation should be corroborated by those actively involved in the educational process.

- Ethnographic research methods that assess the contextual variables within which change occurs should be included in program evaluation.

In an attempt to determine the extent to which vocational and transition oriented services were available to secondary age services in the American context Fairweather, Stearns and Wagner (1989) gathered survey data from 1450 school districts. Fairweather et al were interested in generating data relating to the following areas: whether the school district served special education students in each disability category; the nature of the education agency responsible for providing services to students; the number of students served by the school district; the richness or paucity of school based resources available to students; and the richness or paucity of community resources available to secondary special education students.

A 20 minute telephone interview was developed on the basis of these areas of interest. The telephone interview was conducted with special education administrators who were knowledgeable about secondary level students and services. The study data were analysed using descriptive statistics. The results of this study demonstrates that the availability of transition related services and post secondary employment opportunities are not equally distributed among school districts and communities. This study showed clearly that the opportunities available to special education students are strongly influenced by demographic characteristics, especially the size of the school district and the wealth of the community. Fairweather et al contended that these findings suggested that model transition oriented programmes tested on a handful of students in a limited number of locations may not prove generalisable. Fairweather et al suggested two key issues for future research (a) the exploration of whether vocational education programmes are as beneficial as having a staff member whose job it is to assist students to find a job and (b) the development of cooperative arrangements between employers and post secondary educational and training institutions.

A study by Frank and Sitlington (2000) provides some insight into the outcomes of transition planning initiatives. This study had the aim of determining whether efforts in the area of transition planning were making a positive difference in the lives of young adults with an intellectual disability. The study compared adult adjustment of adults with an intellectual disability who had graduated in 1985 and 1993. The class of 1993 had received transition planning which was consistent with state and federal initiatives in this area. The study was designed to answer two questions: (a) were graduates with an intellectual disability from the class of 1993 better off than their counterparts from the class of 1985 as young adults one year after leaving school? and (b) is the current status of young adults with an intellectual disability satisfactory.

Data related to the class of 1985 had been previously collected as a component of an earlier study of students with disabilities. As part of this study of students with an intellectual disability a survey instrument was designed to provide a range of data including: demographic information about each participating student; demographic information about their high school programmes; participant functioning one year after graduation relative to current life circumstances (eg, marital status, living arrangements, leisure activities) and employment (eg, location of current job, wages per hour, hours

worked per week); and participant perceptions of their high school programme. Two data collection instruments were developed to collect data from the class of 1993 participants. The first of these instruments focused on demographic and other school-related information while the second instrument focused on participant functioning.

Taking into account the economy and other factors that changed in the period between 1985 and 1993 Frank and Sitlington found that young adults with an intellectual disability who graduated from the class of 1993 were better off than those who graduated eight years earlier. A substantial increase (18%) was identified in the rate of involvement of individuals with an intellectual disability in post secondary education and training programs. This participant group also demonstrated consistently better outcomes relating to employment than the class of 1985. In particular the class of 1995 showed a substantial improvement in wages earned per hour and numbers in full-time employment. Greater numbers of workers who graduated in 1993 reported receiving pay increases than those who graduated in 1985.

Greater numbers of 1993 graduates were living independently although the increase was not particularly substantial. Frank and Sitlington attribute the relatively low rate of independent living to the proportion of participants who were attending post secondary education and training programs. The young adults who graduated from the class of 1993 were significantly more positive about the high school educational programmes in which they were enrolled. In particular, 1993 graduates believe the programmes prepared them well for obtaining and keeping a job. Despite the overall gains in outcomes for those students who graduated in 1993 Frank and Sitlington contend that a number of areas continue to need improvement. These include: efforts to continue to increase enrolment in secondary vocational education and training that is available to all students; efforts to place young adults in community based employment with natural supports found in their work environment; a focus on improving the community based employment rate and the full time employment rate; increased efforts to transition students with an intellectual disability into post-secondary education and training programmes (this specific issue will be explored in the next section of this review).

Grigal, Test, Beattie and Wood (1997) conducted a study designed to evaluate the transition component of individualised education plans (IEP's). The IEP's related to 94 high school students aged between the ages of 18 and 21. The students were labelled as having: learning disability; mild and moderate intellectual disability; and emotional/behavioural disorders. Fifty students were labelled as having a mild or moderate intellectual disability. The researchers reviewed Individual Transition Plans belonging to the students and evaluated to what extent transition plans had been implemented.

Grigal et al found that while the majority of transition components would be considered to meet many of IDEA's mandates, most lacked many of the elements of best practice in terms of transition planning. Specific findings included: vague statements of student outcomes and activities, responsible personnel and timelines; lack of long-range planning and annual revision; and lack of best practices (for example – opportunities for interactions with people without disabilities). These findings were largely consistent across the three disability groups involved in this research. However, it is interesting to note that while the group of students labelled as being moderately intellectually disabled had more comprehensive transition plans than other students, only two students among

those reviewed had responsibility for transition plan goals. This suggests that decisions are made, and responsibilities assumed, by individuals other than the student with an intellectual disability.

A policy study conducted from 1992 to 1994 investigated how three American states implemented transition services for youth with disabilities (Furney, Hasazi and DeStefano 1997). The three states involved were selected because they were considered to be exemplary in their efforts to develop and implement transition policies, practices and services. Data for the study were collected through 74 qualitative interviews with key policy makers and implementers and relevant documentation was reviewed. Young adults with an intellectual disability themselves were not interviewed for the purposes of this study. Analysis of research data resulted in the identification of seven themes which appear to contribute to the successful initiation and continuation of transition policies, practices and services. These themes were:

- the presence of values and beliefs in creating an environment conducive to the implementation of transition policies and practices
- using direct policy approaches to create changes related to transition
- paving the way for change by uniting leadership and advocacy
- building collaborative structures to promote systemic change
- using the results of research and evaluation to inform change efforts
- building the capacity for long-lasting change
- looking ahead – linking transition and other restructuring efforts.

Furney et al conclude that while there is no single way to implement transition requirements, the findings of their study suggest a “set of promising practices” which can enable schools and communities to translate policy into action.

The link between self-determination and positive outcomes was explored by Wehmeyer and Schwartz (1997). The Arc’s Self Determination Scale developed by Wehmeyer and Kelcher (1995), a self-report measure of self-determination, was used to measure the self-determination of 80 high school students with an intellectual disability. A follow-up survey was conducted to gather information about this same group of students nine months following their exit from high school. A limitation of the study is that while the first phase of the study involved the direct involvement of students, the follow-up phase designed to measure adult outcomes collected data from the student’s parents. Study findings showed that self-determined students were more likely to have achieved more positive adult outcomes including being employed at a higher rate and earning more per hour than their peers. Wehmeyer and Schwartz interpreted these findings as indicating that the promotion of self-determination as an educational outcome is necessary. To acquire the skills that lead to self-determination, students need to learn how to access resources they will need as adults, communicate interests and preferences, set and monitor achievable goals, plan and manage the use of time, identify and solve problems, and self-advocate. This study highlights the need to conceptualise the process of transition more broadly than simply relating to employment.

Best practice – Implications for New Zealand transition initiatives

This section of the review of transition to adult life for young adults with an intellectual disability has demonstrated that the transition from education to adult lives is more complex than is sometimes acknowledged. Specifically, transition represents more than simply a movement or process from school to work. One of the most challenging aspects of transition and transition planning for young people with an intellectual disability is fostering and aiding a transition toward socially valued, “adult” and stimulating roles (Mitchell 1999). Transition planning needs to incorporate a range of options and activities that include a focus on employment, but that also consider other aspects of adult life including adult education, social relationships, supported living, and community participation and leisure. The importance of all these areas of adult life have been comprehensively explored within other reviews conducted as part of this National Health Committee project.

Transition planning and transition related services have been identified as critical to ensuring that young people with an intellectual disability are appropriately supported through the process of experiencing adult life. Research has identified a number of factors or elements associated with transition related activities which are considered currently to represent ‘best practice’ in the area of transition. These components are outlined below and provide some direction in terms of future transition planning and transition related initiatives with the aim of supporting New Zealand young people with an intellectual disability to experience fulfilling adult roles within their communities.

- At a governmental level, strategic policy and operational planning is urgently needed in the area of the provision of quality transition services for all young people with an intellectual disability. Clearly this will also require descriptive and evaluation research on current provisions. Also the strategy needs to be intersectoral and involve both Education and Work and Income policy responsibilities.
- Young people with an intellectual disability must remain at the centre of transition planning whereby their views, preferences and interests are taken into consideration. Transition planning must empower people and should therefore be based on more than infrequent meetings with professionals. Those working with young people need to be creative about developing processes which fully include them as active participants. A clear distinction also needs to be made between the transition needs of the young person, and those of their family.
- Linked to the preceding point is the need to promote knowledge of, and the skills necessary to achieve self-determination. Young people with an intellectual disability who are self-determined have been found to experience more positive adult outcomes.
- Transition planning and programming efforts must start earlier in students’ lives. Early intervention transition programming may relate to more positive outcomes for students as they enter their adult lives.
- Transition and transition related planning is not just about employment therefore conceptualisations and approaches toward transition should be broadened to

reflect this point. Transition should focus on all aspects of personal development. (See reviews on Relationships, Community participation, Support for daily living, Work and Education for further information relating to these areas of adult life for adults with an intellectual disability.)

- The focus of applied research must be expanded to address the preceding point. Unless all aspects of a person's life are addressed by educational efforts it is unlikely that young adults will be: involved in supportive and intimate relationships, maintaining their own homes, experiencing personal satisfaction, making and acting responsibly on personal choices and decisions, advocating for themselves, engaged in meaningful employment or other daily activities.
- Opportunities for adult education or further education must be included in transition planning and the development of transition services for people with an intellectual disability.
- There needs to be a greater emphasis on enabling young people with an intellectual disability to engage in real work. Work is seen by young people as a necessary 'stepping stone' toward achieving a more independent adult status.
- Vocational training within the educational setting should be accompanied by 'real' work experience so that skills learned can be applied in the employment environment.
- Flexibility within the benefit system is necessary to encourage young people with an intellectual disability into employment and to ensure they are not disadvantaged financially by seeking work.
- The development of local services to ensure that a greater range of post-school options are available to young adults with an intellectual disability. In the absence of a range of adult service options transition planning can become a meaningless exercise.
- Particular attention needs to be paid to the needs of young people with an intellectual disability and high support needs. This group of young people have been identified as failing to achieve positive adult outcomes.
- Collaboration between all individuals and organisations involved in transition planning is consistently highlighted as critical to successful transition planning

ADULT EDUCATION FOR ADULTS WITH AN INTELLECTUAL DISABILITY

Introduction

It is becoming clear that without the skills that come from a good education, people will be disadvantaged in society. People who have been labelled disabled and who lack access to educational programming will be that much more disadvantaged (Alan Roeher Institute 1996: p ix).

As the previous section of this review highlighted, opportunity for adult education is an important aspect of the transition to adult life for young adults with an intellectual disability. Upon considering this issue it is clear that there is still a great deal of work that needs to take place to ensure that **all** adults with an intellectual disability actually receive on-going access to educational opportunities. The intense focus on employment in both the transition area, and in the field of adult services has contributed to a serious lack of attention to the topic of adult education with most researchers working in this area agreeing that people with disabilities continue to be under-represented in post-secondary education.

Methodological issues

Before proceeding with this review it is necessary to address two methodological issues which were encountered in the process of conducting this review. Both issues relate to the diverse use of terminology within the adult education literature. First, in assessing the literature on adult education it became clear that a number of different terms are used to describe educational activities that adults with an intellectual disability engage in after they have exited the secondary school system. The terms used most frequently were: adult education; further education; tertiary education; and post-secondary education.

“Post secondary education” tends to refer to the education that young adults with an intellectual disability access during their final years of schooling within the education system and is usually used to describe education received between the ages of 18 and 21 in age appropriate settings (for example community colleges, polytechnics or universities). Post-secondary education is often considered as part of transition planning and other transition related initiatives. Tertiary education refers to education received within the university, polytechnic or college environment. The term “further education” is commonly used in the British context to describe education that occurs in the university, polytechnic or college environment. “Adult education” is a broad term used to describe education accessed by adults with an intellectual disability during their adult lives, for example adult literacy programmes.

The second problem that was encountered was related to the labelling of students with disabilities in the post-secondary or adult education sector. In assessing the information that was available it became clear that while in many cases adults with an intellectual disability were included in the findings of a number of studies in this area, they were often part of an ill-defined group of students who carried a range of labels including those with psychiatric disability, learning disability, physical disability and sensory disability. Although adults with an intellectual disability are commonly referred to as people with a

learning disability in the British context, the term “learning disability” tends to have a different meaning in the tertiary education literature. In this field and in other countries learning disability refers to people who do not (necessarily) have an intellectual disability but do have a specific difficulty with some aspects of learning and may need educational support as a result (for example students with dyslexia).

Furthermore, many research articles (particularly in the area of tertiary education) were described as including students with disabilities. This usually meant that the study included young adults and adults with physical or sensory disabilities. To avoid confusion, all research material used in this review relates specifically to young adults and adults with an intellectual disability. Where a study has involved students with an intellectual disability as well as other students labelled as having other types of disability the distinction is made clear.

What is adult education?

Adult education largely falls into two categories. The majority of adult education is connected with vocational training and other employment initiatives designed to enhance a person’s potential for obtaining and maintaining a job. Such initiatives have been described within the Transition section of this review. Vocational issues including training has also been included in the review titled “Work for adults with an intellectual disability”. In the section focused on transition for young adults with an intellectual disability the research literature signals clearly the need for a range of alternative post-secondary options to be available to this group of people. Furthermore, it appears that the focus on employment, and employment related initiatives, has contributed to the lack of attention paid to non-vocational adult education issues and initiatives (Riches 1996).

Traditionally, students with an intellectual disability receive special education services in the secondary school environment until they are 21 years old. Growing numbers of parents, researchers and practitioners have questioned whether this practice is age-appropriate and have advocated that these students receive instruction in similar settings to those experienced by their same age peers without disabilities (for example, Fisher and Sax 1999).

Most vocational or other post-secondary education options have tended to occur in segregated environments. It has only been recently that real emphasis and research attention has been placed in inclusive post-secondary options for young adults and adults with an intellectual disability. Currently competitive employment, supported living, and lifelong educational opportunities are aspects of life that many people with an intellectual disability, and their families, aspire to.

Attending college is a desirable outcome for many students exiting the secondary school system (Grigal, Neubert and Moon 2001). This experience may be attending a few classes at a local community college or full-time attendance at a four-year college or university. However, attending college is seldom an option for students with significant disabilities such as an intellectual disability, autism, or multiple disabilities. Follow up studies of these individuals indicate that 14 percent or fewer pursue post-secondary education (Peraino 1992; Wagner, D’Amico, Marden, Newman and Blackorby 1992).

Research has confirmed the advantages of age-appropriate post-secondary opportunities for young adults with an intellectual disability. The findings of a study of the post-secondary outcomes for individuals with a mild intellectual disability (Patton, Polloway, Smith, Edgar, Clark and Lee 1996) led the authors to conclude that educational supports should be available to young adults with an intellectual disability in order that educational programmes and opportunities are provided through local community colleges, and vocational- technical schools. In the view of Patton et al, this would increase the likelihood that students will stay within the educational environment and pursue advanced training.

The importance of age appropriate activities for people with an intellectual disability (including the opportunity for adult education) is illustrated by Calhoun and Calhoun's (1993) study of the effect of age-appropriate activities on the perception of an adult with an intellectual disability. Calhoun and Calhoun undertook this study to explore the effect of age appropriate activities on the perception of adults with an intellectual disability. They were specifically interested in determining how a person's participation in age appropriate activities would affect how they were perceived by other people on a number of different dimensions: estimated intelligence quotient; estimated reading level; social distance; and likeability. Calhoun and Calhoun's study showed statistically significant differences in the way that the same women were perceived in the two videos. In summary, chronological age-appropriate activities led to the women being perceived as having a higher IQ and reading level. The findings of this study offer empirical evidence to support the development of age-appropriate educational opportunities for young adults with an intellectual disability.

A theoretical framework for inclusive adult education

A framework for understanding the nature of inclusive higher or tertiary education has recently been put forward. In a recent paper Nunan, George and McCausland (2000) address two questions: Why is it important that universities aim for inclusive education? and how can universities achieve this aim? Nunan et al contend that the type of person (graduate) that an educational institution seeks to develop is influenced by decisions made about the ideal balance between rights and responsibilities of the individual and society. Nunan et al illustrate this point with the following example: an educational system can reproduce existing economic power structures by excluding those who cannot afford to attend; it can bring together future networks who become the economically advantaged elite; or it can reproduce non-representational forms of power to advantage the already advantaged.

By contrast, Nunan et al suggest it is possible to aim for an educational system that works to facilitate greater participation, democracy, equality, and emancipation for all. This type of education system bears a close relationship with inclusive education. Two ideas relating to inclusivity in higher education are apparent. One is the notion that inclusivity is linked to liberal ideals, while the second is based on the understanding that inclusivity is derived from critical approaches.

The liberal view of inclusivity focuses on increasing participation and success in higher education, especially by individuals who have traditionally been excluded on the basis of gender, socio-economic status, age, disability, race, and ethnicity. Greater participation of

these groups of people is usually achieved by broadening the base of recruitment, and selection, and provision of support in various forms to promote the achievement of success. Nunan et al assert that inclusivity framed in this way is largely to do with manipulating the inputs and processes and little to do with challenging outcomes that perpetuate unequal or oppressive social and economic structures.

The critical construction of inclusivity has a focus not just on the factors directly affecting access, participation and success but also the factors for **judging** success and by whom and how success is determined. Such an approach is concerned with ensuring the decisions about what is included in the curriculum are made according to the basic human values of participation, democracy, equality and emancipation. In taking a critical approach to inclusivity the traditional view of excellence must be challenged, that is instead of excellence being linked to individual achievement, Nunan et al argue that excellence should be gauged by the ways in which the curriculum and teaching, and learning and assessment convey values associated with inclusivity.

Nunan et al argue against narrow and elitist responses to market forces and instead assert the need for inclusivity to build social good as well as individual benefit, enrich and make transparent the curricula, and to “recognise the gift of value to the community.” They also argue that curricula should focus on outcomes – on what sort of professionals, citizens and individuals are shaped for the benefit of society. This paper outlines a theoretical framework for inclusive education that is not specific to students with an intellectual disability but does, however, provide framework for thinking about the inclusion of students with an intellectual disability within the tertiary education environment.

What types of adult education have been provided for adults with an intellectual disability?

Currently, formal tertiary education for people with intellectual disabilities is not available in many geographic areas, but where it is available, courses normally focus on work skills, work experience and a general topic called lifeskills (Reid and Hitchcock 1996).

As a result of the greater emphasis on post-secondary education there is a body of literature available which describes a number of programmes designed to meet the educational needs of adults with an intellectual disability.

Frank and Uditsky (1988) provide a report on the On-Campus project based at the University of Alberta, Canada. The On-Campus programme represents one of the first attempts to include students with an intellectual disability in post-secondary settings. The project involves young adults with an intellectual disability and provides an integrated post-secondary education within the university environment. The On-Campus initiative was a result of the vision of parents and advocates who felt that the options available to young people with an intellectual disability when they completed their high schooling were lacking. In particular, traditional vocational options such as sheltered workshops were not part of their vision for the future.

Eleven students were accepted into the programme when they graduated from secondary school system at the age of twenty. Similarly to a number of the transition oriented

vocational training programmes described earlier in this review, students were accepted to take part if they genuinely wanted to experience this type of post-secondary option. The On-Campus project was committed to accepting a diverse group of students including those with multiple and profound disabilities. On-Campus staff included a coordinator, instructors, personal care attendants (for students with physical disabilities) and volunteers. Three main goals comprised the basis of this project: friendship; normative and enriching experiences; and employment.

Person-centred planning strategies are used to plan a student's program with particular effort placed on understanding past experiences and current needs. The process helps to define the student's strengths, talents, and interests. Students may receive instruction from On-Campus staff or university tutors in the area of finances, computers, conversational skills, roles and responsibilities, library skills, creative writing, English literature, health issues, and personal safety. University classes that have been integrated into students' programmes have included Home Economics, Drama, Music, English Literature and Outdoor Education. The students' plans also include potential social activities that may assist in the development of relationships.

The positive gains for students achieved through the On-Campus programme have been tempered by a number of barriers. Prejudice and bias continue to be evident within some university departments, for example the assumption that people with an intellectual disability cannot learn to read and write so why waste time trying to teach them. A general lack of understanding of the importance of relationships was another problem along with the tendency for some faculties to be interested in the On-Campus students as research "subjects" only.

Panitch (1988) describes another Canadian initiative, the Community Integration through Cooperative Education Program (CICE). Situated at Humber College this programme is based on the principles of individualisation and integration and is the direct result of the efforts of a parent determined to ensure that his disabled son had the opportunity to experience post-secondary education. The project relies on the personal willingness of teachers, support staff and students to become involved, rather than an organised attempt on the part of the institution to legislate acceptance. At the time of writing, Panitch reported that 32 students had been involved in the CICE program. In contrast to most post-secondary programs where students enter post-secondary settings through the transition process, a number of adults with an intellectual disability came from the sheltered workshop environment, and for some, CICE replaced years of staying at home with parents.

The CICE programme at Humber College is two years in duration with nine students being accepted onto the course every year (a total of 18 students at any given time). Unlike most students with an intellectual disability who access post-secondary education, those involved in CICE are free to access the range of opportunities that the college has to offer: courses; labs; guest lectures and poetry readings; work placements; aerobics and intra-mural sports. After an orientation period the CICE students are encouraged to choose an area of vocational interest or "major". Activities related to their major are accompanied by tutoring in literacy and practical math. All students with an intellectual disability on this course are tutored by peer tutors who are students from human service courses on fieldwork placement with CICE. As well as providing academic support placement students fulfil a critical role of opening up a wider social network to the CICE

students. Panitch contends that the success of the programme is illustrated by several factors. First, applications to the CICE programme far exceed the available number of placements. Secondly, the attrition rate for the course is virtually nil, and thirdly, 76 percent of CICE graduates are working either full- or part time in their chosen field within a few months of graduating.

Salovitta (2000) describes a pilot project in Finland where adults with a mild to severe intellectual disability participated as “guest students” in mainstream education in a range of post-secondary environments including vocational schools, institutes and university faculties. This project was based on the Canadian On-Campus programme (previously described) and in the Finnish context was named Kampus. The project functioned for five years from 1995-2000, employed two facilitators and included 15 students during that period. The students involved in the project were individually placed in regular educational institutions in accordance with their own choices. Decisions about future studies were made using person-centred planning techniques.

A significant barrier to the success of Kampus was evidenced very early in the process of matching students to preferred post-secondary options. Very few institutions were willing to accept students with disabilities even if they were only seeking guest status (as was the case in the Kampus Project). This meant that the project was limited to only a few “accepting” institutions. At the point that a student was accepted by an institution the facilitator asked for one or more volunteers among the non-disabled students to support the Kampus student in class. Individualised education plans were written for all students at the beginning of the Kampus project.

Four men and eleven women took part in the project. Their ages ranged from 16 to 51 years and the median age was 18 years. Fourteen students had received their education in special education classes. The exception to this had received no formal education at all. Seven students were classed as having a mild intellectual disability, six students were classed as having a moderate to severe intellectual disability and one student had a physical disability.

Saloviita reported that social goals were the most frequently sought outcomes of the Kampus Project. These included the development of social relationships with other people and the strengthening of self-esteem. Other important goals were those of self-regulation, self-control and the functional skills needed in the community and everyday life. The degree of participation of the students in classes depended on their level of disability, and on the ability of the facilitator to adapt the curriculum. A typical programme for most of the students that took part in this project included training in functional community skills with a secondary emphasis on literacy.

The young adults who took part in the Kampus project were received with a mixture of attitudes from non-disabled students. It appeared that those students with a mild intellectual disability were more readily accepted as regular members of the class than students with a moderate or severe intellectual disability who were only tolerated or superficially accepted. The attitudes toward this project were unsurprising given that the integration of students with disabilities in regular schools is rare in Finland. Both teachers and non-disabled students found themselves in a new and confusing situation. As a result, the students who participated in the Kampus programme experienced help, but not friendship, from non-disabled peers.

The students themselves reported that they enjoyed their studies and were highly motivated by the programme. In general, families also reported feeling satisfied with the progress that their (young adult/ adult) children had made. Facilitators involved with the Kampus project evaluated the programme positively reporting improvements in the functional skills, self-confidence and social development of the students with disabilities. Saloviita concluded that for inclusive programmes to survive they require support from both parents and professionals. Insufficient support from disability professionals was given as the reason for the discontinuation of the Kampus programme.

Hall, Kleinert and Kearns (2000) depict the efforts of a post-secondary program based in Jessamine County, Kentucky, the College Connection Programme. The programme is designed to include students with moderate and severe intellectual disabilities in more age appropriate settings during their final years in the school settings. The initiative described by Hall et al was based at Asbury, a small, liberal arts college and involved a collaborative relationship between Asbury College and the Jessamine County Board of Education. As the students participating in the post-secondary program were legally still high school students (despite the fact they were aged between 18 and 21) the school system contributed staff, materials, transportation, and liability insurance. The college's contributions came in the form of allowing the students' access to college classes and activities at no cost to the students' or the school system. The college was motivated to be part of this post-secondary initiative for students with an intellectual disability because it represented an opportunity to strengthen its relationship with the community and the school system, and because it offered non-disabled students important life experiences, diverse perspectives, and a knowledge of appropriate support strategies for students with disabilities. Unlike the majority of other post-secondary, campus based programs, students with disabilities actually identified and attended a range of academic courses offered by the college. These included: Introduction to Social Work; Family Studies; Education Technology; Ecology; Radio Production. Students also attended a range of physical education classes. The Jessamine County project relied on the involvement of non-disabled student volunteers (as it appears is the case with most post-secondary education projects).

Hall et al list the benefits of the programme as they apply to all those involved. For students with moderate and severe disabilities the programme is credited with providing more **academic** learning opportunities, increased opportunities to participate in age-appropriate leisure activities, and the development of vocational skills and attainment of work experience. Non-disabled college students identify the programme as providing unique opportunities to develop friendships with a variety of individuals, more hands-on learning experience for students in human services professions, and an increased knowledge of teaching students with diverse learning styles. Parents and families also were enthusiastic about the positive aspects of this program. Being involved in the planning associated with this programme facilitated a better understanding of the needs of their sons and daughters as young adults. Furthermore, parents themselves were provided with an increased network of support from other parents, professionals, and the community. Parents also reported that their sons and daughters experienced an increase in their circle of friends.

Finally, the College itself reported the benefits of this program. First, the scope of learning opportunities for both staff and students were enhanced through this program.

Linked to this was the opportunity for future teachers to be prepared to include all students in the context of general learning. Secondly, the College recognised the long-term benefits of collaborating with the school system, the community, and other professional institutions. Hall et al contend that this program needs to continue to concentrate on enabling students with disabilities to participate as fully as possible in college courses, and the college environment.

An assumption which has only recently begun to be challenged is the notion that at the completion of the high-schooling years (often at the age of 21) young adults with an intellectual disability have come to the end of their educational options. Mertz (1997) provides an overview of the range of options that high-school graduates with an intellectual disability can access in the American context. Mertz identifies three main options for further education for adults with an intellectual disability: community colleges; vocational schools; and traditional four-year colleges or universities. Community colleges provide the opportunity for students with disabilities to continue with their education while living at home, in combination with employment, or while they are in the process of deciding on future goals. Mertz provides some examples of community college courses designed to meet the needs of adults with an intellectual disability. A college in Monterey, California provide an Independent Living Skills course which teaches skills necessary to enhance independence (eg, balancing chequebooks).

As well as including this kind of life skill instruction, Taft College (also located in California) has taken college-based education to another level by offering the Transition to Independent Living Program which couples the life skills course with a 22-month campus-dormitory stay. The aim of this course is to replicate that natural progression (for many non-disabled students) from the world of high school to the world of work via community college.

Mertz also reports on other educational institutions which also provide campus experience to young adults with an intellectual disability, including Lesley College, a private liberal arts college which began its Threshold Program, a residential program for students with severe learning disabilities in 1982. The students involved in this course would not typically succeed in a degree program therefore the program “tries to prepare students for independent living, work, and the real world.” In the first year of this programme students gain exposure to three specific career paths: child care, human services; and business services. During this time they also study a variety of independent living skills, for example, decision-making, money management, and understanding disability. In the second year of study the students focus on one of the career areas previously mentioned in order to prepare for employment as day-care assistant, support staff in the office environment, or retail positions.

Kirkpatrick and Earwaker (1997) described a slightly different educational experience for adults with an intellectual disability. As tutors involved in the delivery of a three year degree course in social and professional studies in intellectual disabilities (located in Winchester, U.K.). Kirkpatrick and Earwaker wanted to include people with an intellectual disability themselves in the delivery of the course. In doing so they hoped that they would be demonstrating the concepts of participation and inclusion, and that people with an intellectual disability would have access to information about the education of potential service workers and the opportunity to influence that education.

Involvement of adults with an intellectual disability in this particular course was achieved through Kirkpatrick and Earwaker's positive relationship with a local self advocacy group. Over a period of three years the involvement of members of this self advocacy group have assumed increasing responsibility within the degree course as lecturers, course planners, and committee members. They are also involved in the selection of students on to the degree course. Adults with an intellectual disability who have taken part in this initiative have identified the following benefits:

- the opportunity for real, paid and diverse work (self advocates are paid for their time)
- a perceived rise in status as lecturers, interviewers, advisors and committee members; the perception of equal status
- openings for new social relationships
- receiving respect for their experiences
- development of self confidence
- being in control
- opportunities to get involved in college life
- the opportunity to inform potential service workers about aspects of service which help or hinder progress
- the opportunity to exert influence over a range of decisions.

It is clear that adults with an intellectual disability involved in this educational process gained a great deal through the experience of being in the "educator" role thus illustrating the diverse ways that this group can continue to benefit from educational opportunities even as adults.

Grigal, Neubert and Moon (2001) provide an overview of post-secondary programs in Maryland which are designed for students aged between 18 and 21 who have significant disabilities (including an intellectual disability). Information on setting, staffing, funding patterns, referral and admission practices and components of the programs are presented. Challenges associated with developing and expanding programs in post-secondary settings are also identified. A questionnaire was developed and used to conduct in-depth interviews with the teachers of programs operating in post-secondary settings.

The review conducted by Grigal et al identified a number of program evaluation and research areas that need to be addressed in order to determine how best to deliver age-appropriate and inclusive educational experiences to students with an intellectual disability.

Grigal et al state that there is a need to:

- collect information on student outcomes (employment, quality of life, independent living status) and whether these differ from the outcomes experienced by students who remain in high school until age 21
- document and compare information regarding the satisfaction of various parties involved in programs in post secondary settings (such as families, students, employers, college staff, college students)
- explore the differences between the high school and the college cultures and how these differences could be bridged

- provide specific examples of the individual models of support operating on college campuses
- examine the differences in secondary school curriculum offered to students with an intellectual disability between the ages of 14 and 18, and those students with an intellectual disability aged between 18 and 21.

In considering the range of post-secondary programmes available to adults with an intellectual disability several issues can be highlighted. It is clear that post-secondary education initiatives and programs for students with an intellectual disability are most commonly incorporated within transition initiatives. This suggests that adults who wish to access tertiary education later in life (ie, after the transition years) may experience difficulty. The literature consistently points to the need for liaison, collaboration, and advocacy to occur in order to achieve access to mainstream educational settings at the post-secondary level. For the most part special education professionals fulfil such a role. Older adults who may not have received any formal education, and who are currently supported by adult services may be disadvantaged in seeking placements in tertiary or other educational institutions. Furthermore, it is also obvious that most post-secondary programmes, while including students within post-secondary environment, continue to provide education in segregated classes which are aimed at the development of life skills rather than the acquisition of academic credit.

Furthermore, the inclusion of young adults and adults within higher education environments is accepted because of the benefits it provides for non-disabled students. Given this fact, it appears there is a need for caution against the possibility that further educational opportunities for adults with an intellectual disability are overshadowed by what their presence can provide for other non-disabled students. However, the positive value of experience and interaction with people with an intellectual disability to those training to work in the education or human service sector has been highlighted in the research literature (Smith 2000).

Literacy and adults with an intellectual disability

What is literacy?

A number of the programmes previously outlined have paid some attention to the issue of literacy. Defining the term “literacy” is the subject of much debate (Roehrer Institute 1990). Literacy is usually defined in one of three ways: Basic literacy; Functional Literacy; and Critical literacy. Basic literacy refers to the acquisition of rudimentary reading, writing and numeracy skills. Functional literacy usually refers to the ability to use reading, writing to achieve one’s own goals and to participate in the social and economic life of the community. Critical literacy refers to the acquisition by individuals and groups, who have been marginalised in society, the means to communicate their experience and interests in public discourse.

In 1990 the Roehrer Institute conducted a study of literacy in the lives of people with an intellectual disability. This study was motivated by the fact that many people with an intellectual disability have difficulty achieving literacy. The study also coincided with the United Nations International Literacy Year with the Roehrer Institute asserting that if the

problem of literacy was to be addressed then those with an intellectual disability must be involved in the policy making associated with this issue.

This exploratory study examined the relationship between literacy and intellectual disability. The study commenced with a review of literature in the field of literacy and intellectual disability. The study also incorporated an analysis of the database of the Health and Activity Limitation Survey in order to examine levels of literacy, labour force status, and poverty among people with an intellectual disability. Also conducted for the purposes of collecting data for the study were face-to-face and telephone interviews with self-advocates, (adults with an intellectual disability) those involved in literacy education, government officials responsible for literacy funding, programs and coordination, program coordinators, and literacy educators.

Effective literacy education in general needs to incorporate a learner centred approach whereby individuals identify their own goals and needs. This is a particularly critical aspect of literacy education with adults with an intellectual disability who are enabled to take greater control of the learning process if this strategy is implemented.

The Roeher Institute study found that there are a number of barriers to literacy which may explain the small number of adults with an intellectual disability who actually gain access to literacy programmes: attitudinal barriers; policy and programme barriers; and barriers to learning. Attitudinal barriers mainly came in the form of other people assuming that adults with an intellectual disability would not be able to achieve literacy – even educators involved in literacy programmes questioned the ability of these adults to learn and therefore did not allow them access to available courses. Policy and programme barriers were identified as including: the way programmes are funded; costs to the individual; eligibility criteria; supports and services; and outreach and linkage. Barriers to learning are multiple and are related to: training and development of educators and tutors; materials; modes of instruction; and linkages with other aspects of the person's life.

The Roeher Institute study concluded that the lack of literacy among adults with an intellectual disability is one of the obstacles to their participation and independence in the community. It has contributed to entrenching poverty, unemployment and low health status in their lives. In 1994 the Roeher Institute published a *Guide to Inclusive Literacy Education*. This publication pulls together practical strategies for conducting literacy education with adults with an intellectual disability and highlights a number of challenges that need to be considered when offering such programmes.

- Students with an intellectual disability frequently do not graduate to the “next step” whether that be a job or an educational milestone. These students stay much longer than the program originally intended and have a tendency to see the program less for education and more for socialisation. Programmes need to have flexibility to accommodate this.
- Non-labelled students who are learning to read and write sometimes feel threatened by the association with labelled students. Consequently they may not choose to use literacy programs that are attended by people with disabilities. This in turn creates the risk of segregation.

- Programmes that provide literacy but do not have the resources to provide adequate supports are faced with a difficult choice. Either they use valuable teacher and volunteer resources to provide attendant care or they only enrol people who can bring their own support people.

Despite the challenges to providing quality literacy education the value of literacy and the implementation of literacy programmes continues to be supported in the research literature. In an Australian study of functional literacy skills in young adults with Down Syndrome, Bochner, Outhred and Pieterse (2001) explored the development of language and literacy skills in a group of young adults with Down Syndrome. Bochner et al were particularly interested in identifying the differences in functional literacy within a group of young adults with Down Syndrome, some of whom had been educated during a period when there was an increase in expectations for achievement and opportunity to learn. Results of this study showed that all but one of the 30 young adults with Down Syndrome who participated in this study had learnt to read, though for some, these skills were limited. There was a positive relationship between age (ie, those born after 1970), and attendance at an integrated school situation, and the achievement of more advanced reading and writing. Perhaps most importantly, however, Bochner et al found that reading provided the young adults who participated in this study a functional daily living skill, and a satisfying recreational activity. Many of the young adults read for pleasure.

Literacy is also critical to improving the communication of people with Down Syndrome. Research has shown that children with Down Syndrome as young as three years succeed at reading single words, and that if children with Down Syndrome participate in early reading and writing that continues throughout their school years they achieve better communication and academic skills than their peers with less literacy experience (Miller, Leddy and Leavitt 1999).

What do people with an intellectual disability want from tertiary education?

It is difficult to find information relating to adult education, and more particularly tertiary education, for adults with an intellectual disability. It is clear that adult education is an area that has not been comprehensively explored in relation to people with an intellectual disability. Such people appear to experience limited opportunity for further education and there seems to be a common perception that tertiary education is not a realistic expectation for people with an intellectual disability. While the last 20 years have seen growing support for the inclusion of children and young people in mainstream educational settings it has only been recently that attention has been paid to adult education for people with an intellectual disability.

Ash, Bellew, Davies, Newman and Richardson (1997) conducted a study which provided important information relating to the views and experiences of students with and without disabilities. In contrast to many other “disability” studies in this area, findings relating specifically to students with an intellectual disability were presented. Ash et al approached their research from the viewpoint that the social experience of education (from the perspective of the students themselves) has frequently been missing from studies focused on further education. This research is especially pertinent given that three of the authors are disabled themselves and had recently completed their education at a residential special school. From their friendships with others who attended the same

school they were aware that their friends had mixed experiences of going to college after leaving school. The research therefore, was developed and carried out by three ex-students in conjunction with two other researchers. The study was designed to explore three main areas:

- what are the views and attitudes of disabled and non-disabled students in colleges of further education to the inclusion of disabled students
- what is the nature and extent of relationships between disabled and non-disabled students in colleges?
- to what extent can it be said that inclusion facilitates social and interpersonal relationships between disabled and non-disabled students?

Three colleges located in South West England were selected to participate in the study, the study had two parts. In the first phase of the study questionnaires were distributed to 200 students in each college. Questionnaires asked about friendships and contacts between disabled and non-disabled students as well as views on inclusion. In the second phase of the research group, interviews were held with students. These involved the following arrangements: first the research team met up to three separate class groups (which included disabled students) at each college; and secondly, the disabled members of the research team met up to two groups of disabled students drawn from various courses in each college. The decision to conduct separate group interviews was made in order to explore the distinct experiences of each group. College plans, proposals, reports on inclusion and statements about equal opportunity policies were also collected as data for the study.

For the purposes of this review only those findings specifically related to the issue of intellectual disability are presented here. The framework of understanding disability for most non-disabled students interviewed appeared to be the medical model of disability. The focus was on the perceived deficits of the individual and what compensations might be needed to counteract their effects. There appeared to be little awareness of any need to address attitudes towards disability. Only a small number of the students taking part in the study said that they had disabled friends. Those who did, identified their friend as having a physical disability. Other students described experiencing difficulty in their social contact with disabled students. Ignorance, embarrassment, guilt and confusion and a sense of “not knowing what to do” were all frequently mentioned.

While many students identified positive benefits of studying alongside disabled students, this approval became more qualified as they distinguished between students with different impairments. In short, the full and equal inclusion of all students whatever their needs was not always seen as practical or possible. The following verbatim comments were provided by non-disabled students who participated in this study.

I think we still need different schools for people with more learning disabilities, because a lot more time needs to be spent with them.

It depends on the disability. I don't think you can - across the board – say that everyone can come. I think it's got to be worked on.

You can reverse the question and say do you think it is right that somebody in a class who is able-bodied, mentally able and everything, should be deprived of as

much education as he needs because of teachers having to spend so much time with somebody who can't cope?

Through the focus group interviews it was clear that anti-discrimination legislation was something that was supported in principle but not always in practice:

It's not fair (to shortlist a disabled person who meets minimum qualifying criteria) because you're singling them out because of their disability putting them straight on the shortlist because they've got a disability.

These comments illustrate very clearly that intellectual disability is something that prohibits further education in a way that other disabilities may not. Non-disabled students' overwhelming support for the principal of inclusion was tempered with qualification, particularly around the inclusion of students with an intellectual disability.

Findings generated through the focus group interviews with disabled students presented here are confined to those that are specifically related to, or have direct relevance to students with an intellectual disability. Students with an intellectual disability educated in discrete units said they had little contact with students outside these groups. Their leisure time inside the college was usually spent with others with "special needs". These students were, however, positive about attending a mainstream college. Some students with an intellectual disability saw inclusion as giving them the opportunity for a more academically challenging education.

We didn't learn much (in special school), we used to do little kiddies' stuff. We didn't do hard work but at college we do hard work and then we learn more.

We didn't do any exams – that was a bit disappointing. If your friends went to different schools and they would talk about the exams and say we were lucky 'cause we didn't get any homework and stuff. But I wish we had 'cause we might have got better at things.

While disabled students were generally positive about the benefits of inclusive education for all students, they also identified some of the negative aspects of inclusion. Disabled students are not always treated well by their peers and can experience feelings of isolation and exclusion as a result. Interestingly, these same students recognised that school years can be an unhappy experience for many children whether or not they have a disability.

This study highlighted a number of core themes. Amongst non-disabled students, there was considerable lack of knowledge about the circumstances of disabled students and disabled people generally therefore social contact between disabled and non-disabled students was not extensive. Non-disabled students seemed to hold contradictory views relating to the rights of disabled students. While non-disabled students supported legislative action to secure the rights of disabled people, and supported the view that social and educational contact with disabled peers will encourage understanding of the difficulties that they might encounter, they were less convinced that inclusive education in the tertiary environment was viable for all students, particularly those with an intellectual disability. These findings strongly indicate a hierarchy of disability whereby people with an intellectual disability are less likely to be viewed as people with a legitimate claim to education in the tertiary environment.

A New Zealand study by Reid and Cretney (1998) provides some answers to the question “what do students with an intellectual disability want from tertiary education?”. Reid and Cretney conducted a study which explored the provision of special studies courses to students with learning disabilities, students who had little prior education, and students with an intellectual disability. The research took place in a Polytechnic which had been offering such courses over a period of ten years and sought information about student learning preferences and styles in order to provide courses which met student need. Research interviewers involved in this study all had prior or current experience of the special studies courses that the Polytech offered.

The study found that nearly all the students with an intellectual disability interviewed for the study recognised that their purpose for attending the polytechnic was to learn or continue learning. Most students emphasised the importance (to them) of improving their reading, writing, and computer skills. Reid and Cretney contend that this concern with literacy and computer skills is a reflection of today’s society and the types of skills that are necessary to succeed in the workplace, and the general community. Students’ had other more personal reasons for attending the Polytech course. The following comments illustrate this point:

... it gets me away from my house

.. it’s a school for grown-ups

You don’t have to pick up rubbish, don’t have to wear a uniform, and you can call the tutors by their first names

... better than at home with mum and dad.

Reid and Cretney make recommendations on the basis of the findings generated through this research. First, formal tertiary institutions should continue to value and provide courses for adult students who require special tuition (particularly in the area of literacy). This will lead to increased participation in the community through extending personal independence and increasing the chances of securing employment. Second, the educational institution and those involved in providing special studies for students with an intellectual disability should also focus on enabling those students to access other student activities. This study found that students enrolled in special studies had limited opportunity to meet other students or to access other courses offered by the Polytechnic.

What are the barriers to developing quality tertiary education programmes for adults with an intellectual disability?

The Roeher Institute study (1996) identified a number of barriers that prevented people with disabilities from taking part in post secondary (or vocational training) in the Canadian context. Such barriers included:

- the criteria for, and attitudes towards accepting students with an intellectual disability were influenced by the role of the specific post secondary institution they were applying to in the community. For example, colleges that viewed

themselves as small scale universities reported more rigid competency based admission criteria and were concerned about “watering down” their academic standing should they accept students with an intellectual disability

- post secondary institutions that operated within a broad definition of learning were more flexible in their admission criteria and were more responsive to accommodating students’ needs and modifying programmes, course structure and course materials
- negative attitudes toward the inclusion of students with an intellectual disability within post secondary institutions were generated by fear, lack of understanding of disability issues, and a lack of knowledge about implementing inclusive practices for such students
- the funding structure for post secondary education for students with an intellectual disability can perpetuate the segregation and labelling of such students. In order to obtain funding to support students to access post secondary education the institution is required to have a designated “special needs program” for students with an intellectual disability. Many students coming from inclusive high schools were resentful and unwilling to be programmed into segregated settings at the post secondary level
- under provisions for student loans. Students with an intellectual disability were sometimes penalised for taking a reduced course load with little consideration for the reasons the student may need to assume a part time status. Penalties were reported as a barrier to obtaining funding. Students with an intellectual disability may need to take fewer courses and may need more time to complete their studies
- few programs certified students with an intellectual disability upon graduation from a specific vocational programme. In these situations students were accepted into a programme but did not complete all the courses so therefore did not qualify for certification according to the institution’s policy. This meant that non-certified students experienced difficulty competing against certified students for employment positions.

Lehman, Davies and Laurin (2000) reported on a project that sought to identify and systematically eliminate barriers to post-secondary education, and to improve students’ potential for having successful post-secondary experiences. The “Aiming for the Future” project included a diverse group of students with disabilities, and included students with an intellectual disability. The findings generated through this project were not presented in a way that differentiated different groups of students’ views, as the researchers found that a consistent range of barriers were evident in the student’s educational experiences in the post-secondary environment.

Four dominant themes were identified. Students’ reported that a general lack of understanding of and acceptance of disability on the part of non-disabled students, staff and faculty impacted on their ability to achieve positive outcomes. A lack of adequate services to support students with disabilities with both academic and non-academic issues was reported as a problem by disabled students. A lack of financial resources and the knowledge of how to access them created a situation which made the task of becoming

increasingly independent very difficult. Finally, the students who participated in this study recognised that their quest for greater independence would be enhanced by self-advocacy skills and training. This project provides very important information relating to the areas that need to be considered when planning or implementing initiatives with the aim of encouraging people with disabilities (including those with an intellectual disability) to access the range of educational opportunities that are available within the community.

Jenny Corbett (1993) outlines the situation relating to the provision for special needs in colleges of further education (FE) in Britain. Corbett identifies that one significant barrier to gaining acceptance of students with disabilities being included in mainstream further education settings is due to the fact that:

All too often those tutors who assume responsibility for students with special educational needs in further education are unused to engaging in any form of ideological struggle. A focus on individual needs and immediate practical problems narrows their perspective (p 68).

Corbett asserts that most of these individuals come from the 'special school' sector and do not have experience or a well developed understanding of the further education environment. It appears that what Corbett feels is necessary to progress toward inclusive tertiary institutions is the promotion of a theoretical framework of inclusivity like that proposed by Nunan et al. Corbett also emphasises the point that special needs initiatives and supports within the further education environment continue to occur within a "caring department" thus perpetuating notions associated with dependency.

A British study by Leicester and Lovell (1997) included 30 adults with disabilities and parents of disabled children and had the aim of exploring their educational experiences. In relation to provision of post-school education, the issue that emerged as the most significant to adults with disabilities themselves was that of vocational training and careers advice. The parents of children with disabilities that took part in this study were aware of and troubled by the lack of post-school provision that their children would one day face. In particular, the parents highlighted the need for educational opportunities pointing out that people with an intellectual disability need more, not less, continuing education. Leicester and Lovell contend that their research findings confirm the need for continuing education provision focusing on vocational and professional training opportunities for people with disabilities, and greater inclusion into mainstream courses.

Mitchell (1999) explored the transition to adulthood from the perspective of both young adults with an intellectual disability leaving the special school environment, and the parents of these young people. The study also incorporated the views of teachers and other professionals involved in the process of transition and transition planning. The teachers and other professionals acknowledged that there had been a recent expansion in the number of college places available to young adults with disabilities, but they expressed a number of professional concerns and reservations. One significant concern was that in some colleges access for disabled young people was still conditional on two factors: first, environmental considerations and questions of disability severity; and secondly, perceptions of "acceptable" students. Mitchell reported that while it was clear that although the young people and their parents thought they were making a choice, it was a choice from a very narrow and specific set of options.

A New Zealand study (McKay, Ballard and Smith 1998) researched the experiences of disability in three tertiary education sites: the University of Otago, Otago Polytechnic, and the Dunedin College of Education. The aim of the study was to ask people with disabilities themselves, teachers and administrative staff, what disability meant to them in the context of pursuing courses, taking part in campus life, and accessing resources that ensured equitable treatment. Data for the study were collected through the use of a questionnaire, and a number of qualitative interviews were held with a selected sample of each participant group.

McKay et al identified a number of factors critical to ensuring that students with disabilities achieve equal access to tertiary education alongside their non-disabled peers. While it is unclear from the description of the participant group included in this paper whether students with an intellectual disability contributed, a number of findings are directly relevant to the issue of this group of adults and their ability to access tertiary education. One significant finding was that a number of students and staff had found it difficult to gain entry to certain vocationally oriented courses. This finding was highlighted by the comments made by a tertiary staff member who asserted that students with disabilities had no place in particular courses:

Considering the nature of this institution it would be unreasonable to expect that we would accept people with a wide range of disabilities eg, blindness, severe learning disability eg, unable to read and write, deafness, in a wheelchair (p 56).

Other tertiary staff attributed the resistance to accepting students with disabilities into tertiary courses to the fact that they were not likely to be employed at the end of their course. One staff person involved in teacher training commented:

To a large extent we are governed by schools who will not willingly have disabled people as teachers (p 56).

This New Zealand study was effective in highlighting the significant attitudinal change that is necessary to ensure that students with disabilities do not encounter additional barriers to accessing tertiary education of their choice.

In 1996 the Roeher Institute conducted a study which explored the issues associated with achieving inclusive post secondary education for people with an intellectual disability. The Roeher Institute is a Canadian policy research institute which promotes the equality, participation and self-determination of people with intellectual and other disabilities. This study of post secondary education for people with an intellectual disability was motivated by the fact that more and more children and youth with an intellectual disability are educated in regular classrooms in regular schools. An entire generation of children and youth with an intellectual disability expect to live in and take part in their communities, to obtain and maintain jobs, and to live independently. It is increasingly common for parents and families also to hold such expectations. The Roeher Institute study focused on institutions which offer post secondary training to people with an intellectual disability. Specifically, the study aimed to identify: how such institutions design accessible, suitable programming for people with an intellectual disability; how they adapt teaching methods and the curriculum to make knowledge more relevant and accessible; how they organise the learning environment; what legal and policy levers support such undertakings; and

how can society and institutions of learning ensure that all learners develop their potential regardless of ability of learning style. Because the study focused on post secondary institutions that were already including students with an intellectual disability the study provided important information about current best practice in terms of adult information. The study identified what contributed to successful adult education programmes.

This study found that educators, and post secondary administrators were more likely to promote the inclusion of students with an intellectual disability if the following conditions occurred:

- support networks for teachers
- in-service instruction by community agencies
- disability awareness workshops
- professional development sessions
- story sharing among teachers and families
- team approaches to individualised programming and accommodation.

Transition planning prior to entering a post secondary institution was found to have beneficial outcomes for the students involved. Transition planning which involved the creation of partnerships among secondary schools, post secondary institutions, families, businesses and community support agencies were found to be components of successful transition planning. Transition planning which incorporated all these features was found to be beneficial in fostering self determination and decision making skills among students with an intellectual disability (see section on transition earlier in this review).

Weir, Tashie and Rossetti (2001) articulate some of the assumptions that have impinged on the ability for people with disabilities to access higher learning.

For twenty-five years powerful advocacy has taken place to assure that all students have real places in their public schools. But, in that same period of time, rarely has college been discussed. For many, there continues to exist a belief that individuals with severe disabilities could never be successful in college. This misguided reality, based on out-dated assumptions about what labels mean in terms of intelligence and competence, is often coupled with paternalism and motivated by a desire to protect people from what is imagined to be a certain failure. These factors work together to make dreams of college seem silly, unrealistic, and even dangerous for some people (p 14).

Weir et al continue to say that along with the assumptions and fears about disability and college success, the entrance criteria that colleges generally use to judge suitability for acceptance constitute a very formidable barrier. College admission criteria continue to be based on narrow definitions of intelligence, potential and academic success. Weir et al explain the American legislative context and its subsequent impact on students with disabilities who wish to attend institutions of higher learning such as colleges and universities. While the Rehabilitation Act of 1973 made it illegal for the vast majority of colleges and universities to discriminate on the basis of disability, it was not until the passage of the Americans with Disabilities Act in 1991 that post secondary institutions began to take this responsibility seriously. As a result the percentage of students with disabilities attending college has increased from 2.6 percent in 1978 to 11 percent in

1997. As Weir et al point out, those students attending college still tend to fit the image of a “traditional” college student and do not tend to include students with severe disabilities.

In this paper Weir et al assert the need for change in this area but caution that in “our haste to move forward some dangerous missteps are occurring.” What Weir et al are concerned about is the propensity for post secondary programs to do little more than move the special education classroom to the college campus. This point had credibility upon looking at the range and type of post secondary programs that are currently available (and are reported on earlier in this section) which usually allow students access to non-academic classes but do not engage with the issues of choice, grades or college credits.

Weir et al commented that:

We must learn from the past and refuse to support the development of special classes or programs on college campuses, for they, like special education classes in public schools, will eventually need to be dismantled in favour of real inclusive choices (p 16).

Best practice in adult education for people with an intellectual disability – Implications for New Zealand educational providers

While this review of adult education for adults with an intellectual disability clearly has illustrated the significant lack of opportunity for continuing education for this group, it has also shown that this issue is increasingly on the agenda within the disability field. Post secondary and adult education programmes and courses are still, in many cases and contexts, in their infancy. However, despite this fact, research does provide some guidance in terms of “best practice” in this area. The following points represent suggestions and recommendations which need to be considered when planning educational initiatives for adults with an intellectual disability in the New Zealand context.

- At a government level, strategic policy and operational planning is urgently needed to address the current inequality and lack of opportunity evident in the area of adult education for young adults and adult students with an intellectual disability.
- It is critical that young adults and adults themselves are involved in the planning and implementation of post secondary and other adult education initiatives. Research clearly indicates that adult education will be more successful if the views, preferences, and interests of people with an intellectual disability themselves provide the framework for progress.
- Attitudinal change is required at an institutional level so that inclusive post secondary or adult education (particularly within tertiary institutions) is seen as important. People with an intellectual disability continue to be perceived as unable to learn. Furthermore, research has identified that non-disabled students, staff, and faculty view the inclusion of students with an intellectual disability as having a negative effect on the status of a particular course, faculty, or institution.

- Linked to the preceding point is the need for critical consideration of the issue of how “academic success” is judged or determined. Young adults or adult students with an intellectual disability may require alternative models of certification or accreditation than their non-disabled peers.
- Educational opportunities in the tertiary environments must be provided in the first instance, in a way that is beneficial and appropriate to students with an intellectual disability. Indirect benefits that are derived from this inclusion for other students, staff or faculty must remain the secondary focus of educational programmes.
- Post secondary education needs to occur in age-appropriate environments. It continues to be common practice for young adults to remain in the secondary school environment rather than to move on to post-secondary settings at the same time as their non-disabled peers.
- Transition planning and transition related initiatives need to include a focus on continuing education for those young people who wish to have access to such opportunities. Transition planning and programmes continue to be heavily weighted toward vocational services and employment related goals.
- It is important that not all adult education initiatives are provided within the context of transition. Many older adults with an intellectual disability who have not received formal education in the past experience additional barriers to accessing adult education.
- A particular focus on Adult Literacy is required to enable adults with an intellectual disability to achieve greater independence in all aspects of their daily lives. Effective literacy education should incorporate a learner centred approach whereby individuals identify their own goals.
- Post secondary and adult education initiatives need to be designed to allow for the degree of flexibility required to meet the diverse requirements of adult students with an intellectual disability. Within the New Zealand educational context it appears that the New Zealand qualifications Authority (NZQA) systems should enable the development of such flexible approaches.
- Real effort and advocacy is needed to ensure that post secondary and adult education for young adults and adults with an intellectual disability are provided in mainstream educational environments. It continues to be common for adult education to occur in segregated settings.

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