A conceptual approach to the work, leisure and retirement education of adults with an intellectual disability

A Conceptual Approach to the Work, Leisure and Retirement Education of

Adults with an Intellectual Disability

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ORIGINALITY STATEMENT

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of another degree or diploma at UNSW or any other educational institution except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

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ABSTRACT

Work, leisure and retirement are fundamental aspects of life for individuals with an intellectual disability, just as with the general population. Many educational efforts have taught knowledge and skills to persons with an intellectual disability to improve their functioning in the work and leisure domains. More recently, retirement concerns have become particularly salient because so many individuals now live much longer. The present study looked at using a conceptual approach to improve education in these three domains. It employed the principles that instruction works much better when it proceeds from an individual=s existing concepts and that instruction should teach useful concepts that an individual can apply to improve his or her real world functioning. This conceptual approach has not been used much with the education of persons with an intellectual disability. In Study 1, sixty adults with an intellectual disability were interviewed to determine their existing concepts of work, leisure and retirement and their work and leisure histories. Most had solid concepts of work and leisure, but with some gaps, particularly in notions of volunteer work and occupational status. Most reported satisfactory work and leisure lives. Most had a relatively poor concept of retirement at best and had done little or no retirement planning. These data suggested some key targets for an educational program to improve their knowledge and functioning in these domains. In

Study 2, these data were used to develop an instructional program that focussed on gaps in knowledge of volunteer work, banking, budgeting and participation in satisfying leisure activities and in retirement planning. This instructional program was delivered over eight weeks to a class consisting of nine adults with an intellectual disability, with some success. This general conceptual approach can be usefully applied to teaching in other important domains with persons with an intellectual disability. They can be taught key concepts which they can use to live their lives more purposely and independently.

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CHAPTER ONE: OVERVIEW AND INTRODUCTION TO INTELLECTUAL DISABILITY

OVERVIEW

This thesis is concerned with the application of a conceptual approach to educational efforts to improve aspects of work, leisure and retirement functioning in a specific group; persons with an intellectual disability. This topic is very broad and several quite extensive research literatures are relevant to the questions addressed. Each area is reviewed in turn, but in some cases relatively selectively, to keep this thesis within reasonable length bounds.

The first section defines intellectual disability, looks at its types and prevalence and examines research on the cognitive, emotional and motivational deficits involved, and at issues surrounding the housing and care of individuals with an intellectual disability. The second section looks at the education and training of persons with an intellectual disability, examining the issues of what, how, where and when to teach. The third section examines aspects of work, leisure and retirement in the general population, as a background for considering work, leisure and retirement in persons with an intellectual disability, which is examined in the fourth section. The fifth section looks at research on education for improved work, leisure and retirement functioning in persons with an intellectual disability. The sixth section defines the term "concept", looks at research on concepts, and examines research on the

concepts held by persons with an intellectual disability. The final section draws together the relevant features of these literatures and states the main aims of the present study.

INTELLECTUAL DISABILITY

This chapter gives an overview of intellectual disability and some issues concerning it. After giving a definition, the chapter looks at issues surrounding classification, causes, prevalence and intellectual and motivational deficits involved. The chapter concludes by looking at some issues surrounding care and housing of persons with an intellectual disability.

Definition of intellectual disability

The category of "persons with an intellectual disability" is very broad. Some researchers consider it a quite artificial (or "social") category because individuals with many varying disorders are placed within it and the range of intellectual impairment of those individuals is very wide (Singh, Oswald & Ellis, 1998; Ghobary, 2005).

Formal definitions used to place persons within the category of intellectual disability have varied over the years (e.g., Zigler, Balla & Hodapp, 1984; Detterman, 1999; Detterman, Gabriel, & Ruthsatz, 2000). The American Association on Mental Retardation (AAMR) has provided several formal definitions, the latest in 2002. The present thesis uses the 1992 definition as the work was begun before the 2002 definition was put forward. Although the 1992 definition has generated some controversy, it is used widely by researchers and

practitioners and will be used here. By the 1992 definition, intellectual disability is a general intellectual deficit. It involves fundamental difficulty in cognition and learning and in performing certain daily life skills.

> "Mental retardation refers to substantial limitations in present functioning. It is characterised by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable, adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18." (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik & Stark, 1992, P. 5).

However, the exact criterion for "sub-average intellectual functioning" may vary from locale to locale. Most commonly, it is an IQ score of 70 or below, as measured by one or more individually administered general intelligence tests. However, the education department in the state of New South Wales (NSW), where the present study was conducted, uses an IQ score of 75 or below.

The AAMR definition also stipulates that intellectual limitations occur at the same time as limitations in adaptive skills, in at least two of the listed skill areas. The latter are skills involved in daily living, and an individual's deficits in them should be related to his or her intellectual limitation. Limitations in adaptive skill areas are common reasons why individuals with an intellectual

disability need community support. However, norms for the relevant skills in each adaptive skill area vary with age (Luckasson et al, 1992).

It is useful to expand on the adaptive skill areas. The first is communication skills: the ability to comprehend and express information through symbolic behaviours. The latter include speech, writing, graphic symbols, sign language and manually coded English, and such non-verbal signs as facial expressions, body movements, touches and gestures. The second is self-care. These skills include toileting, eating, dressing, hygiene, and grooming. The third is home living, which includes skills related to functioning within the home. These include clothing care, housekeeping, property maintenance, food preparation and cooking, planning and budgeting for shopping, home safety, and daily scheduling. Related skills to this adaptive skill include orientation and behaviour in the home and nearby neighbourhood and the communication of choices and needs.

The fourth is social skills. These include skills related to social interaction, which include recognising feelings of other people, assisting others, initiating, engaging in and terminating interactions, providing positive and negative feedback, regulating one's own behaviour, being aware of peers and peer acceptance, forming and fostering friendships, controlling impulses, conforming to rules and laws, and displaying appropriate sexual behaviour. The fifth is community use. These skills involve appropriate use of community

resources, such as public transport, shopping facilities, churches, libraries, art galleries, and so on. The sixth is adequate <u>self-direction</u>. This relates to skills involved in making choices, such as learning and following schedules, initiating activities appropriate to a given setting, completing required tasks, seeking aid, resolving problems confronted in familiar and novel situations, and demonstrating appropriate assertiveness and self-advocacy skills. These skills are needed in the workplace.

The seventh is <u>health and safety.</u> These skills involve safe and healthy living; eating a balanced diet, exercising regularly, preventing and treating ailments, basic first aid, and basic safety considerations such as wearing seat belts. The eighth is <u>functional academics</u>. This involves applying skills typically learned at school to daily life tasks (Luckasson et al, 1992). Examples are writing, reading, using basic math concepts, and using basic science concepts such as those applying to the physical environment. The ninth is <u>leisure</u>. Skills in this domain include choosing and self-initiating interests, using and enjoying home and community leisure facilities and recreational activities alone and with others, playing socially with others, taking turns, and expanding one's repertoire of interests, awareness and skills. The final adaptive skill area is that of <u>work</u> that involves skills related to holding full or part-time jobs. Skills involved include specific job skills (such as welding), appropriate social behaviour in the

workplace, and related work skills such as completion of tasks, awareness of schedules, ability to seek assistance, take criticism, and manage money.

However, as mentioned, the AAMR offered a revised definition in 2002, a definition which was not used for this thesis. It really makes little difference for the present purposes which is used. This definition is as follows (Luckasson et al, 2002),

> "Mental retardation is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18."

Diagnosis of intellectual disability

Individuals who may have an intellectual disability can come to the attention of practitioners in a variety of ways. Some cases are obvious at birth, or even before birth (e.g. in specific syndromes such as Down, detected with prenatal testing) while others may come to light only in the early years of schooling. A child may function well enough in daily life but have increasing trouble with the abstract tasks of schooling, and eventually be referred for testing. Many do not look disabled and may function well enough outside the six-hour school day (in the United States). They perform poorly only in school, leading to the term "six hour retardation" (e.g. Beirne-Smith, Ittenbach, & Patton, 1998).

Diagnosis using the AAMR definition involves an expert examiner measuring IQ and adaptive behaviour skills. The IQ test used should be an individual intelligence test, in which only one examiner tests one person, so that the examiner can closely monitor responses. Some commonly used individual IQ tests are the Stanford-Binet Intelligence Scale, Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC), and the Kaufman Assessment Battery for Children.

There are several specific tests of adaptive behaviour, such as the Vineland Adaptive Behaviour Scale (e.g. Beail, 2003). Assessment of adaptive behaviour skills should consider an individual's cultural background and community environment. Different communities may emphasise certain skills more than others, for example. In addition, each individual has a profile of strengths and weaknesses. He or she may be weak in some, such as communication, but strong in others, such as community living.

Diagnosis of intellectual disability may have some complications. One is that IQ test norms below 70 often are based on normative samples with very few individuals (Flynn, 1985). Another complication is the Flynn effect (Flynn, 1999), the increase in raw scores on IQ tests in industrialised nations since at least the 1920s. This rise averages about three IQ points per decade. While there is some evidence that the increase at least partly involves rising population intelligence (Howard, 2001), specific test norms may quickly become obsolete.

Test publishers periodically update norms but whether an individual is tested at the start of or near the end of use of a particular set of norms may affect the likelihood of diagnosis of intellectual disability (e.g. Kanaya, Ceci & Scullin, 2003). Kanaya, Scullin and Ceci (2003) recently argued that this problem literally may be a matter of life and death in some cases; for instance if deciding whether a criminal should be diagnosed as intellectually disabled and thus should escape capital punishment.

Finally, there can be problems in differential diagnosis of intellectual disability and <u>learning disability</u>. (It should be noted that the term learning disability is defined in different ways and in the U.K. is equated with intellectual disability). By definition, intellectual disability involves a general intellectual deficit, while a learning disability involves one or more specific intellectual deficits. The usual idea is an individual has at least a roughly average IQ score but very poor ability in a specific area such as spatial relations, or has a large discrepancy between IQ score and a score in one particular domain (e.g. Smith & Strick, 1997, P. 87). (NSW does not use the term "learning disability" but rather the related concept of "Problems in key learning areas"; Special Education Handbook for Schools, 1998).

The American "Individual with Disability Education Act" defines learning disability as follows,

"Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing or motor handicaps, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage." (Smith & Strick, 1997, P. 87).

A complication is that some individuals who really are best categorised as having an intellectual disability may actually be classified as having a learning disability, for extraneous reasons. (Polloway, 1985; MacMillan, Gresham, Bocian & Lambros, 1998). Criteria may not be consistently applied or parents may ask for the apparently more palatable label of learning disability (Gresham, Siperstein & Bocian, 1996). Available funding may even affect diagnosis. For example, in the United States, individuals diagnosed as having an intellectual disability receive more funding and educational authorities may use the category sparingly to reduce expenses. In addition, parents may have to approve the diagnosis and may reject the category of intellectual disability.

Types of intellectual disability

Intellectual disability can be classified in various ways. Which category scheme is used typically depends on purposes at a given time and there is a history of classification efforts.

Classification by severity

One classification method is by the severity of the intellectual deficit, with four major categories typically being used (e.g. Polloway, Smith, Chamberlain, Denning & Smith, 1999). The usual categories are as follows. Mild disability involves the IQ range from 70 to 55; moderate from 54-40; severe from to 39-25; and profound is under 25. About 90% of cases fall in the mild category, and often are considered largely to be due to early environmental deprivation, and in particular low levels of stimulation and poor diet (McDermott & Altekruse, 1994). Indeed, the prevalence of mild intellectual disability correlates with poverty, and more environmental stimulation may decrease its prevalence (e.g. McDermott & Altekruse, 1994).

NSW uses three major intellectual disability categories, based on severity (Special Education Handbook for Schools, 1998). The categories are used to guide school placement and future employment. The categories are based on IQ score, usually assessed with the WISC III, and possible deficits in adaptive behaviour. The mild category involves an IQ score between 55 and 75, but not necessarily with deficits in adaptive behaviour. Those in this category usually are placed in special classes with up to about 18 students. However, some are

integrated with regular students for most of the school day. As adults, many may gain competitive employment. The moderate category involves an IQ score between 40-54 and deficits in adaptive behaviour, usually measured with the Vineland Test. Individuals in this category often are placed in special self-contained classes, with a maximum of nine students, on a regular school campus. A range of options exists, however. The individuals may be integrated with regular students for a few subjects such as music, art, or physical education. As adults, a few may gain jobs but most only can hope to work in sheltered workshops. The severe category involves an IQ score of 39 or below and deficits in adaptive behaviour. These individuals may be placed in special classes or in special schools or in a regular class. As adults, some may work in a sheltered workshop, while some will participate in a day program. NSW provides special funding for students in these categories, with a range of services available.

For those in the mild intellectual disability category, a "Learning Assistance Program", also typically used for students with a learning disability (dubbed problems in key learning areas) also is available.

Classification by cause

Cases of intellectual disability also may be classified by cause, if the cause actually is known. This scheme can be useful in some circumstances and is not incompatible with classification by severity. Intellectual disability has

many known causes; pre and post-natal injury, lack of environmental stimulation in early life, and various genetic syndromes such as Fragile X syndrome, for example (e.g. Beirne-Smith et al, 1998). However, the cause or causes may be unknown with some individuals. Three specific classifications by cause are described here to illustrate this method of categorisation and to expand the present description of intellectual disability.

A common genetic cause is Down syndrome, which involves the affected individual having 47 chromosomes instead of the usual 46. It has a prevalence of about 9.2 cases per 10,000 live births in the United States (Epstein, 1995). The possibility of having a child with Down syndrome increases with the mother's age; one chance in 13,000 at age 25, one in 365 at age 35, and one in 30 at age 45 (Crickle, Wald & Thompson, 1987). The child with Down syndrome typically has some or all of the following characteristics; a flat facial profile, a poor Moro reflex, hyperflexibility of the large joints, loose skin on the back of the neck, slanted palpebral fissures, small round ears, and a single Palmer crease (Epstein, 1995). Most individuals with Down syndrome fall in the mild (IQ 55-70) and moderate (IQ 30-54) categories, but some are in the severe category. They have difficulties with language, communication, and problem solving skills. Their spoken language may be difficult for others to understand because of a thicker tongue and possibly a malformation in the mouth.

As recently as 1983, life expectancy of individuals with Down syndrome was quite short at about 25 years, but it has now risen to an estimated 55 years, with many individuals living into their sixties and seventies (Zigman, 2004). However, virtually all adults with Down syndrome exhibit changes in brain chemistry associated with Alzheimer's disease by age 40. By the age of 60 to 70 years, 50 to 60% individuals develop dementia (Zigman, 2004; Epstein, 1995).

Another category is Foetal Alcohol syndrome, caused by the mother consuming too much alcohol during pregnancy. The alcohol reduces the oxygen and nourishment needed for normal foetal cell development in the brain and other organs and causes mental and physical problems (Abel & Sokol, 1991). Physical problems include growth deficiencies, skeletal deformities, facial abnormalities, organ deformities, and central nervous system abnormalities such as a small brain. Most cases fall in the mild to moderate IQ range, but a few fall into the severe category. In milder cases, there may be such problems as a short attention span and hyperactivity (Abel & Sokol, 1991). Some researchers believe that cases of foetal alcohol syndrome are significantly under-reported (e.g. Abel & Sokol, 1991). However, overall stated prevalence in the United States is one in 500 to 700 live births (Kozma & Stock, 1993) and in Australia is 1.7 in 1000 live births (Harris & Bucens, 2003). The prevalence typically is higher in indigenous populations. In Native Americans, it is 29.9 per 10,000 live births (Chavez, Cordero, & Becerra, 1989), and the Southwest Plains Indians

have an incidence of one per 102 live births (May, Hymbaugh, Aase, & Samet, 1983). In Australia, the indigenous Aboriginal population has a prevalence of 4.7 per 1000 live births (Harris & Bucens, 2003).

A third type is Fragile X syndrome, a genetic disorder caused by an X chromosome mutation. Persons with Fragile X may have a range of physical, cognitive, behavioural and emotional characteristics. More males are affected and typically have more severe deficits (Hagerman & Hagerman, 2002). Prevalence estimates vary with perhaps one in 4000 males being affected, but many fewer females showing symptoms even if they have the genetic deficit (Hagerman & Hagerman, 2002).

Individuals with Fragile X syndrome typically have delayed speech and language development, with disruption in the flow of speech. There is repetition of words and sounds, swings in pitch, and rapid speech with problems of rhythm and echolalia. Behavioural and emotional characteristics are often autistic- like, with hand flapping, biting, poor eye contact, obsessional interests and resistance to changes to routines. Around 10-15% of males tested have IQ scores in the borderline or mild disability range (Harris-Schmidt, 1998). Fragile X is non-progressive; the disorder is not degenerative. The males tend to learn at a slower pace. Interestingly, females with Fragile X tend to have a specific learning disability rather than intellectual disability. For instance, they may have

a deficit in mathematical ability but function at near average levels in other domains.

<u>Prevalence of intellectual disability</u>

The prevalence of three syndromes was outlined in the previous section. This section will look at the prevalence of intellectual disability in general. The mathematical model underlying the normal curve would suggest that about 2.2 percent of the population would have an IQ score of 70 or below, although the population distribution of IQ scores is not perfectly normal. However, the actual prevalence today apparently is much lower, at less than 2% (Howard, 2001). In the United States, National Centre for Education statistics suggest that the proportion of school children with an intellectual disability has progressively dropped; from 2.2% in 1976-7 to 1.3% in 1997-8 (Howard, 2001). In the 1996-7 school year, 24.4% of children aged 18-21 in special education programs were labelled intellectually disabled, versus only 12.6% of those aged 12-17 years and only 9% of those aged 6-11 years.

The prevalence of severe intellectual disability is fairly low and the rate has changed relatively little over the last few decades. Roeleveld, Zielhuis & Gabreels's (1997) extensive review concluded that the prevalence of severe disability in various locales over the last few decades has stayed at a roughly constant "true prevalence" of 0.31% of the population. A study of Down syndrome cases in an area of England found little change in prevalence from the

1950s to the 1990s (Bound, Francis & Harvey, 1995), although Bermegjo, Martinez and Luisa (1998) found a decline in Down syndrome cases in Spain from 1976, which they attributed to the availability of prenatal screening (introduced in 1969) and abortion.

The prevalence of mild disability is more difficult to determine because norms and labelling practices differ across time and nation, as mentioned earlier (Flynn, 1985; Roeleveld et al, 1997). Skarbrevik's (1990) review of many studies concluded that its prevalence declined in Scandinavian nations from 1961 to 1989, which he attributed to increasing population intelligence.

In Australia, prevalence estimates vary and different studies may get slightly different results. The Australian Institute of Health and Welfare (2004) estimated that in 1998, 503,000 people, or 2.07% of the population, had one or more intellectual disabling conditions, with 212,700 persons, or 1.1% of the Australian population, reporting their main disabling condition as that of an intellectual disability. A total of 301,900 of these individuals, or 1.6%, also had a severe or profound restriction for a core activity. A high incidence of intellectual disability was reported for individuals aged 65 or older, which was thought to be due to dementia-related conditions. Among children and adolescents, the prevalence of intellectual disability is generally higher for males.

Beange and Taplin (1996) looked at the prevalence of mild and severe intellectual disability in a sample of 20-49 year olds living in the northern suburbs of Sydney. The overall prevalence was 3.31% of the population, with 2.19% for mild disability and 1.12 for severe disability. The prevalence of Down syndrome was 0.96% per one thousand of population. A total of 38% of the sample lived in institutional care.

Cognition in and specific cognitive deficits in intellectual disability

Intellectual disability is considered to be a general deficit. The affected individual has difficulty performing a wide range of intellectual tasks. Guided by varying theoretical frameworks, researchers have extensively examined cognition in persons with an intellectual disability to try to determine the precise nature of their intellectual deficits (Detterman, 1999). One hope was the general deficit might spring from just one or a few more specific deficits, and perhaps extensive training might overcome these and greatly improve overall intellectual functioning. [However, it should be noted that much research and practice in intellectual disability has been based on a behaviouristic perspective (Howard, 1995).]

Detterman (1987; 1999) reviews the history of research on cognition in persons with an intellectual disability. He divides the research effort into three main phases. The first stage (from the year 1850 to the early 1900s) was marked by efforts to identify and classify persons with an intellectual disability

and to arrange the best living conditions for them. In this period, no distinction was made between the intellectually disabled and the mentally ill. The second stage (early 1900s until after World War II) was concerned with cataloguing their capabilities, such as what they could learn and remember. In the third stage (after World War II until the present day) researchers looked for specific cognitive deficits. An unhappy conclusion was that there was no single cognitive deficit. Every major cognitive process investigated seemed to be affected (Detterman, 1987; 1999).

Many researchers in this third, modern stage have been guided by two major approaches to understanding intellect in general and to the causes of individual differences in intellectual functioning (Anderson, 1986). The first partly derives from the psychometric tradition (e.g. Detterman, 1999) and particularly, from Spearman's (1904; 1927) notion of g. Spearman argued that humans differ in a largely innate general ability he called g. G is the power to abstract, to see similarities and differences, and to reason. Performance of every intellectual task involves g. Some tasks involve more g than others and thus are more "g-loaded". Jensen (1982; 1998) argued that mental speed is the basis of g. There are several sources of evidence for the existence of g. One is the general factor that emerges from factor analysis of performance on a variety of intellectual tasks (Jensen, 1998). For instance, if a large number of participants perform a large number of intellectual tasks, a factor analysis of scores on the

tasks usually reveals evidence of a general factor that aids performance on all, with some tasks more than others. Another is a line of physiological research suggesting that g could be a kind of neural efficiency (e.g. Jensen, 2000; Van Rooy, Song & Stough, 2005).

The rationale of many traditional IQ tests is that they measure g. So, by this view, intellectual disability can be regarded as due to deficits in the neural underpinnings of g. Individuals with an intellectual disability score low on IQ tests and perform poorly on many other intellectual tasks because different pathologies (due to chromosomal, neurobiological, metabolic or environmental causes) lead to low g (e.g. Dobbing, Clark, Corbett, Hogg & Robinson, 1984). There is some evidence that persons with an intellectual disability tend to differ most from individuals of normal intelligence on tests that are most g loaded (Spitz, 1982), i.e., tests of reaction time and perceptual speed (Jensen, Shaefer, & Crinella, 1981; Nettelbeck & Kirby, 1982).

The second major approach derives largely from cognitive psychology. The cognitive approach involves analysing cognition into representations and the processes acting on those representations. A key assumption is that cognition can be analysed into a small set of elementary processes (perhaps no more than 20) that are combined and recombined (e.g. Kail & Bisanz, 1992; Massaro & Cowan, 1993) to perform tasks. It should be noted that these

approaches are not incompatible. Researchers have been integrating the psychometric and cognitive approaches (e.g. Sternberg, 1985).

Much recent work with the cognitive approach uses an emerging "standard model" of memory that proposes several memory "structures" (e.g. Howard, 1995). By this model, information from the environment first is held briefly in sensory registers and some information then may be moved to working memory. The latter is like a mental workbench. It has a very limited capacity, holding only a few elements for a few seconds without rehearsal (Sweller, 1999). When learning a new task, the rules and specific characteristics of the problem that are to be applied are held and manipulated in working memory. Long-term memory holds information for much longer, sometimes up to a lifetime. It holds information that allows persons to perceive, think and solve problems. Information in long-term memory largely is organised around concepts, which are described in much greater detail later. For now, a concept can be defined as a mental representation of a category (e.g. Smith & Medin, 1981).

Researchers applying the cognitive approach to intellectual disability have compared the cognitive structures and processes of persons with an intellectual disability with those of non-disabled individuals. For example, two theoretical approaches in this vein are those of Ellis and of Zigler (Detterman, 1987). Ellis's deficit theory proposed that intelligent behaviour is based on a set

of cognitive processes, one or more of which may be deficient in individuals with an intellectual disability. Researchers should try to determine those deficient processes (Ellis, 1969; Ellis & Cavalier, 1982). Zigler's (e.g. Zigler, 1969; Zigler & Balla, 1982) developmental theory proposes that individuals with an intellectual disability develop at a slower rate and reach a lower asymptotic developmental level than normal persons.

As mentioned above, Detterman (1987; 1999) summarised the findings of much research in this vein by noting that every cognitive process apparently was affected in intellectual disability. The deficits include those in attention, memory, strategy use, transfer and generalisation (e.g. Gargiulo, 2003). Others include mental slowness, a small knowledge base, and impoverished concepts (described later in this thesis). Some specific examples are outlined here to give the flavour of this research area.

The first example concerns problems with attention. Attention can be defined as the variety of internal processes that govern how persons access information from the environment (Iarocci & Burack, 1998). Two types of attention aid learning; selective attention and sustained attention. The former involves filtering (focussing on relevant information), orienting toward key stimuli (e.g. looking for the source of a sound), integration (noting the relations among features of say, a visual stimulus) and priming (the influence of prior processing of information on a new task with different processing demands)

(Iarocci & Burack, 1998). The latter, sustained attention, involves monitoring environmental changes over a long period to complete a task (Iarocci & Burack, 1998). The general observation is that persons with an intellectual disability have problems focussing and sustaining attention (Brooks & McCauley, 1984).

Another deficit area is memory. Memory deficits tend to be greater with increasing severity of intellectual disability (Drew, Hardman & Logan, 1996). Ellis (1963) found short-term memory deficits. Some researchers suggest that the memory deficits arise from the attention deficits mentioned above. Persons with an intellectual disability have difficulty attending to relevant stimuli and have inefficient rehearsal strategies to hold the information in memory long enough to process it (Borkowski & Day, 1987; Brooks & McCauley, 1984).

Persons with an intellectual disability perform more poorly in various visual perception tasks, such as those involving depth perception (Courbois, 1996; Fox & Oross, 1992; Silverstien, Ulfeldt, & Price, 1970). Courbois (1996) found various visual imagery deficits in persons with an intellectual disability. Participants were asked to perform four tasks involving visual imagery. The first involved generation of an image in the visual buffer from its representation in long-term memory. The second involved image maintenance. The third involved the inspection of different parts of the mental image and the fourth involved mental rotation of the image. Participants had difficulty maintaining images, which probably accounts for their poor scores on psychometric tests in

which they are required to memorise an image to solve a problem. This visual imagery weakness may be one reason why persons with an intellectual disability perform poorly in solving spatial problems (Rieser, Guth, & Weatherford, 1987).

Persons with an intellectual disability also have problems with knowledge and skill generalisation and transfer (Stokes & Baer, 1977; Agam, Salzberg & Slowitchek, 1987; Langone, Clees, Oxford, Malone & Ross, 1995). Generalisation can be defined as the transfer of knowledge and/or skills learned in one context to new situations and/or related tasks. An example of the lack of generalisation is learning how to use a specific soft-drink machine but being unable to then operate a similar machine located elsewhere. For those with a severe intellectual disability, generalisation may be extremely difficult (Brown, Nietupski & Hamre-Nietupski, 1976; Sternat, Messina, Nietupski, Lon & Brown, 1977). Researchers have tried to increase such transfer by providing instruction in a variety of settings, by using many examples and materials, and by extensive verbal instruction of multiple applications of knowledge (Garguilo, 2003).

Persons with an intellectual disability also are much more likely to have language deficits (Warren & Abbeduto, 1992). Language develops more slowly and vocabulary and grammar are more limited (Morrison & Polloway, 1995). Young people with a moderate to severe intellectual disability frequently

encounter serious difficulty acquiring words (Barrett & Diniz, 1988; Romski & Sevcik, 1989). They often do not develop spoken language skills even after much language and speech training.

Language is crucial to school learning and poor language skills may be a major reason why persons with an intellectual disability have problems with many academic tasks (Warren & Abbeduto, 1992). In the United States, speech and language problems are the most common secondary disability (Epstein, Polloway, Patton & Foley, 1989). Language problems also impact socially. Being unable to communicate easily with others can hinder integration into mainstream society (Polloway & Smith, 1982). Indeed, some researchers argued that language deficits are so important that language training should be viewed as an integral part of all daily activities (e.g. Schiefelbusch, 1981).

Finally, it still is controversial whether individuals with specific intellectual disability syndromes (such as Down syndrome) have particular patterns of cognitive deficits and particular ranges of problems. Detterman (1999) argues that the intellectual deficits are the same regardless of the cause. However, there is some contrary evidence to this view. For instance, individuals with Fragile X syndrome may show specific cognitive deficits, such as problems with short-term memory, auditory processing, learning abstract concepts, and planning (Hagerman & Hagerman, 2002). However, strengths may include visual learning, whole work learning, number and pattern

recognition, and incidental memory. Conners, Rosenquist and Atwell (2000) examine some specific deficits in Prader-Willi syndrome.

In recent years, with improving techniques to study the living brain, more researchers have been tackling the neurobiology of intellectual disability (e.g. Lawrence, Lott & Haier, 2005). However, firm conclusions remain difficult to draw from this line of research.

Motivational and emotional deficits

Persons with an intellectual disability also tend to have some motivational and emotional problems, which may derive in part from the intellectual deficits (e.g. Zigler, 1973). One is poor motivation to learn, perhaps due to repeated failures to learn or great difficulty in doing so. They may find it difficult to initiate and/or continue any learning tasks for this reason. Some research suggests that they tend to have an external locus of control, where outcomes of behaviour are perceived as due to circumstances beyond their control. They have little or no confidence in themselves, and look to others for cues and guidance (Bybee & Zigler, 1992). These repeated failures may lead to a style of learning and problem solving characterised as "outer directedness" (Zigler, 1973). Repeated failures may lead to a sense of "learned helplessness" (Seligman, 1975), a belief that there is nothing an individual can do to deal with a situation.

Housing and caring for persons with an intellectual disability

Persons with an intellectual disability need to be housed, just as everyone else does, but also may need special caring arrangements as well. How this should be done is a major societal concern. What may be done in an individual case varies greatly with the severity of the disability and other factors, such as available family support.

Until the mid 20th Century, the dominant practice typically was some kind of segregation from mainstream society, which could take various forms. One example is isolation within the family, along with day schooling in special schools. A second is residence in a special institution, with relatively little contact with the outside world.

From the 1960s, such segregation began to be frowned upon and the principle of <u>normalisation</u> became salient. Normalisation can be defined as allowing individuals to live as close as possible to normal persons (e.g. Hogan & MacEachron, 1980). Nirje (1969, P. 181) defined normalisation as follows:

> "Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."

The guiding idea was that, rather than being placed in residential institutions or only in segregated schools, individuals with an intellectual disability should be integrated in the community as much as possible, and integrated in typical life styles which do not call attention to their disability.

A practice deriving from the normalisation principle is <u>de-institutionalisation,</u> closing down the large residential institutions that used to house many persons with an intellectual disability, and housing them instead in the community. They could be placed within their family home or in special group homes with a few others, supported by paid staff. De-institutionalisation of psychiatric hospitals was carried out on a large scale from the 1960s in the United States, with very mixed consequences. One criticism is that many former psychiatric patients ended up living on the streets.

De-institutionalisation of persons with an intellectual disability has also been carried in Australia, but not completely. For instance, the study by Beange and Taplin (1996) mentioned earlier found that 38% of their sample in northern Sydney still lived in institutions. Ashman, Suttie and Bramley (1995a) determined the residential circumstances of 446 persons with an intellectual disability living in Queensland and Western Australia. De-institutionalisation had affected only 30% of them. The surveyed persons lived in a variety of residential settings, but often had little say in their caring and residential arrangements. Bigby (1998) found that residential primary care still was common in Victoria, along with supported employment, and day or leisure activity. Often the results of de-institutionalisation are positive for the former inmates (e.g. Young, Sigafoos, Suttie, Ashman & Grevell, 1998; Young & Ashman, 2004).

Some private organisations that cater to persons with an intellectual disability promote many different housing options and choices. An example is Hornsby Challenge, a non-governmental organisation in northern Sydney that caters for adults with an intellectual disability, who are aged from their early twenties to the early seventies. In 1985, Hornsby Challenge started moving clients from its residential institution to the community, and in 1987 became one of the first organisations to close its institution (Van Dam & Cameron-McGill, 1995a). The former residents first were moved into group homes housing three to four people, but this proved unsatisfactory for some clients. The organisation now provides a variety of options; housing in group homes with three residents, housing with one other person without a disability, living alone, boarding with a family, living in the individual's family home, and housing in a nursing home. In line with the normalisation principle, each individual's preferences are taken into account, and his or her housing arrangement may change over time with changing preferences.

Hornsby Challenge also aims to promote integration into the community, emphasising use of community facilities and services. [Indeed, the Australian Institute of Health and Welfare (AIHW) Report, published in 2002, found that persons with an intellectual disability were less likely to use community services and facilities or to participate in community activities.] Hornsby Challenge noted that many previously institutionalised clients relied on

institutional staff as their main social support and encouraged staff to be facilitators to help forge relationships between clients and persons in the community. The starting point was the interests of the person with the disability, aiming for contacts with persons with similar interests. The next step was to explore any known contacts. The third step was to make contact with the potential group and introduce the idea of a person with a disability becoming a member of that group. Next, a staff member would visit the group to determine the suitability of the individual with an intellectual disability to join. He or she then accompanied the individual to the group. From there on, the staff member's job was to facilitate interaction within the group and then to fade out this support gradually. Having withdrawn from the group, the staff member would drop back every few months to see if the client had been accepted within the group and to look for opportunities to foster closer ties (Van Dam & Cameron-McGill, 1995b).

How well a previously institutionalised person will cope with community living may depend on many factors, such as the extent of the disability, extent of community supports, money available and so on. For instance, an interesting study by Pedlar (1992) that compared de-institutionalisation practices in Sweden and Canada, illustrates some of the issues. De-institutionalisation was more successful in Sweden partly because that nation allocates large sums to caring for de-institutionalised persons with an intellectual disability and service

staff generally are paid professionals. Unpaid community helpers are few. Ratios of staff to group home residents are low, and the residents have the resources and help to pursue individual interests and activities rather than only being able to take part in large group activities.

In contrast, Canada has a "residual" social welfare system that provides services only after such alternatives as the family or the private sector has been insufficient. Government aid is perceived as temporary charity, and receiving it carries a stigma. Many de-institutionalised individuals were returned to communities not well prepared to care for themselves. Group homes visited in the study had too few staff and residents attended three activities (dances, swimming, and bowling) in large groups that were not necessarily their individual preference. Primarily unpaid helpers, such as volunteers, parents or friends, provided social support. An outcome of this policy was that the person who had no friends, or for whom paid support is not available, was more likely to be socially isolated. Because of the lack of funding, competition is fierce for both service workers and families for limited resources, which helped to create a confrontational and adversarial system. The Australian model to some extent mirrors the Canadian model, with more funding and staff needed.

Chapter Two

EDUCATION OF INDIVIDUALS WITH AN INTELLECTUAL DISABILITY

Having now defined intellectual disability and having considered some of the problems persons with an intellectual disability may face, this thesis now can consider educational issues. The above-mentioned cognitive, motivational and emotional deficits mean that an individual with an intellectual disability typically will have problems with the curriculum in a normal school. In general, there are difficulties in learning across all academic areas, with reading comprehension and arithmetic often being particular problem areas (Drew, Hardman & Logan, 1996). The severity of an individual's academic problems will vary with the degree of intellectual disability, and other factors such as motivation and family support, however. The difficulties are likely to worsen as the individual progresses through the school system. The curriculum becomes more complex and cumulative over successive years, and more difficult to cope with. The individual with an intellectual disability typically will fall further and further behind non-disabled peers. For instance, NSW integrates many persons with an intellectual disability into normal primary grades, but increasingly they need special education classes in upper primary and secondary school. Most leave school by age 16 years. The basic skills of accuracy of counting, recognising numerals, telling time, and understanding quantity are important for

future employment and independent living but persons with an intellectual disability often complete formal schooling without mastering these skills (Broome & Wambold, 1977; Grise, 1980).

Therefore, several general issues arise, which partly parallel issues about education for all persons. Some major issues are as follows:

1. What knowledge and skills can and should be taught, and why?

2. At what particular ages should particular knowledge and skills be taught?

3. What teaching methods should be used and at what ages?

4. Where should education take place; in special schools, in regular classrooms, and so on?

5. What theory should instruction be based on; Piagetian theory, Behaviourism, cognitive psychology?

For many years, much education for persons with an intellectual disability was based on behavioural principles, but now a more cognitive approach often is used, as in the present study.

The above issues are intertwined and can be difficult to disentangle. What knowledge and skills should be taught may determine the methods used to teach, which themselves may vary with age. As well, there are various derivative philosophical questions, such as whether persons with an intellectual disability always should be integrated in regular classrooms. Research may help

inform answers to the philosophical questions. However, specific policies are societal decisions.

The literature on these topics is large and this section will only examine some key issues relevant to the present study. It also will examine some specific studies that have employed various teaching methods.

<u>Some general goals of education for persons with an intellectual disability</u>

Mass education in an industrial society typically has a number of goals, which overall are largely concerned with preparing individuals for life in society and for participation in the work force. Schooling typically involves teaching factual knowledge of the world, such as geography, history, chemistry, etc. (Hirsch, 1987), basic skills such as reading and writing, and general workplace related skills such as punctuality, concentration on workplace tasks and deference to authority, and specific workplace skills such as welding. Education also may involve teaching appreciation of art, music and literature, health enhancing skills, and so on. Teaching the above to some extent can be general goals for persons with an intellectual disability, but, given their intellectual deficits, training in other knowledge and skills also may be indicated.

Gagiulo (2003) argues that a major educational goal for persons with a mild or moderate intellectual disability is to enhance their ability to live and work independently in a community, with as little dependence on others as

possible. Patton, Smith, Clark, Polloway, Edgar and Lee (1996) suggest four major educational goals; competence in basic life skills, successful integration into schools and community settings, successful employment, and independent living. Various authors have argued for self-determination as an important educational goal (e.g. Wehmeyer, Agran, & Hughes, 1998), especially in making choices directly related to the direction of a person's adult life. Sigafoos, Feinstein, Damon and Reiss (1988) argue that "behavioural autonomy" is a key goal, which is a progression from dependence on others for care and guidance to self-care and self-direction. Aspects of behavioural autonomy include the individual being able to earn wages, manage and spend his or her own money, and make such lifestyle decisions as how to spend free time and determine where to live and work.

General Living Skills

Teaching factual knowledge is important but much educational effort for persons with an intellectual disability has involved teaching a variety of useful skills (Patton et al, 1996). Some examples of these skills are as follows. Functional skills are those used regularly in daily life, such as following directions in a cookbook, completing a job application and changing money. Functional academic skills are those usually taught in schools, such as being able to read, even if only in a limited way (e.g, to read safety words such as "EXIT" and "FIRE ESCAPE") to read cooking recipes, and words and

numerals on coins. Teaching functional skills is at the core of the program for mild and moderate individuals with an intellectual disability (Gargiulo, 2003). Then there are specific vocational skills such as welding and related skills important in the workplace such as punctuality, appropriate dress, following instructions, and so on. Community skills are those involved in accessing and participating in community activities, an example being able to use a public swimming pool. Self-help skills are those involved in taking care of one's own needs independently, and may include those involved in personal hygiene. Some researchers argue that the teaching of self-help skills is crucial (e.g. Reid, 1982; Van Etten, Arkell, &Van Etten, 1980; Whitman & Scibak, 1979). Indeed, governments and caregivers could save much time and money if many persons with an intellectual disability could better take care of themselves.

Acquiring and adequately using such skills, as those above, may be difficult because of the generalisation problem mentioned above. A general goal is to teach transferable skills (Stokes & Baer, 1977) and special methods may be needed to promote generalisation. For instance, initial instruction may be in a classroom and later instruction in a natural setting, which may also promote better retention.

An illustration of the teaching of useful functional skills is the training of those skills involved in money management. Money-handling skills are

particularly important in the present study and so some relevant studies will be covered in some detail here.

Handling money is an important real world activity. There are a variety of component handling skills of varying complexity, from being able to count change to investing successfully in the stock market. A fairly basic-level skill is just being able to make a purchase; (e.g. to hand over enough cash to a vendor to buy something). Slightly more complex skills may involve purchasing with a cheque or a credit card. One can include social aspects of transactions, such as not using notes of unnecessarily large denominations when vendors are unlikely to have change.

A variety of studies have aimed to teach basic-level purchasing skills to persons with an intellectual disability, typically by training participants to use one of various strategies. For example, tourists in a foreign nation may use one simple purchasing strategy when they do not speak the language and are unfamiliar with the notes and coins. They just hold out the coins and notes in a hand and allow the vendor to pick out what is needed and to give change.

A variety of other purchasing strategies have been successfully taught (e.g. Marholin, O'Toole, Touchete, Berger & Doyle, 1979). One strategy involves giving a trainee a pre-specified sum (e.g. $10), which he or she then presents to a vendor (McDonnell & Hardman, 1989). A second strategy is to overcome inability to count by teaching what denominations of money are

appropriate for various daily transactions, and to train selection just by physical appearance rather than a count. Gardill and Browder (1995), for instance, taught participants to select coins by appearance for vending machines, and to give a $1 note to buy a snack at a convenience store and a $5 note to buy lunch. A third strategy is the "next dollar" strategy, also known as the one-more-than technique (Colyer & Collins, 1996; Van den Pol, Iwata, Ivancic, Page, Neef, & Whitley, 1981; Denny & Test, 1995; McDonnell & Ferguson, 1988; Test, Howell, Burkhard, & Beroth, 1993; Westling, Floyd, & Carr, 1990). The trainee is taught to count out and to hand over one dollar more than the vendor's stated price. A fourth strategy is to train persons to use a calculator to determine if they have enough money for a given purchase (Frederick-Dugan, Test, & Varn, 1991; Matson & Long, 1996; Nietupski, Welch, & Wacker, 1983; Sandknop, Schuster, Wolery & Cross, 1992; Wheeler, Ford, Nietupski, Loomis, & Brown, 1980). This skill may be taught along with instruction in grocery shopping.

Other very specific purchasing strategies have been taught. For instance, the time delay strategy involves the introduction of a prompt concurrently with the target stimulus. The trainer delivers this prompt to the natural cues of the target setting (Gardill & Browder, 1995). Another is the least-intrusive prompt strategy (Alcantara, 1994; Colyer & Collings, 1996). Here, the trainer gives a

series of prompts, with increasing assistance as needed, until the participant makes the desired response.

After a review of many studies of money- handling skills, Browder & Grasso (1999) made several recommendations for practice and for future research in this area. First, instruction should begin with purchasing skills because such training introduces the purpose of money and the consequences of its use in the community. The second is to simplify the intellectual demands of money use or to build on pre-existing academic skills. The third is to use prompting and fading strategies to teach money use. Time delay and least-intrusive prompts are good techniques. The fourth is to train and test for generalisation to community contexts, which can be enhanced by use of simulations, role-playing, natural cues, and training in multiple settings.

The fifth recommendation is an important one for the present thesis. Instruction should include training in more complex money management skills, such as banking, bill paying, and budgeting. Also, one might add such new skills as use of debit cards and internet shopping. Persons with an intellectual disability need to learn budgeting and banking skills to gain financial autonomy and to carry out successful financial planning in retirement, for example.

Although as yet, relatively few studies have tackled these more complex money-handling skills, some studies that have done so are as follows. LaCampagne and Cipani (1987) and Cuvo, Davis, & Gluck (1991) taught

participants to use money for self-support through learning to pay bills. Other studies have involved teaching participants such banking skills as use of automatic teller machines, writing cheques, completing banking paper work, transacting with human tellers, and opening a savings account (McDonnell & Ferguson, 1989; Shafer, Inge, & Hill, 1986; Bourbeau, Sowers, & Close, 1986; Zencius, Davis, & Cuvo, 1990). Few studies have involved training in budgeting. Wilson, Cuvo, and Davis (1986) trained participants to shop with a $25-per-week budget. More recently, Suto, Clare, Holland and Watson (2005) linked financial decision-making capacity with degree of intellectual disability, and also suggested that access to basic skills education and everyday decision-making opportunities may enhance money-handling capacity. There seem to be no available studies that have taught participants to use money with others in mind (e.g. to purchase gifts, donate to charity, and help in fund-raising projects for schools).

<u>Where to teach</u>

For many years, in Western nations, individuals with even a mild intellectual disability largely were segregated from the mainstream school population. There was even debate on the extent to they could learn at all (e.g. Detterman, 1999). However, in the latter decades of the 20th Century, societal attitudes toward the disabled began to change with the normalisation principle mentioned earlier. A view is that the disabled have the same rights to education

as anyone else, including the right to be educated in a normal school (e.g. Foreman, 1996; Ashman & Elkins, 2005). Philosophical principles/practices linked to normalisation which have been applied to schooling are "mainstreaming" and "inclusion" (Foreman, 1996). The distinction between the two can be difficult to draw and different practitioners may use the terms in somewhat different ways. Mainstreaming usually implies that persons with an intellectual disability should be integrated in mainstream schools and classes as much as possible. An argument was that non-disabled peers could provide a powerful model for language, behaviour, dress, and social skills. Inclusion can be taken as a more extreme view. Persons with a disability not only should be integrated but regular schools should be modified as much as necessary to achieve this integration.

In practice, there are various options in between complete segregation and complete inclusion. A child may spend some time in a special school and then be integrated for some months in a regular school before returning to the special school. There may be a special classroom within a regular school, with children integrated with normal children in some classes such as art and physical education. In NSW, the favoured policy now is inclusion where possible (Special Education Handbook for Schools, 1998; Dempsey & Foreman, 1997; Dempsey, Foreman & Jenkinson, 2002). When integrated, the child may go through a slowed down version of the regular school curriculum.

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Research support for the benefits of such inclusion with cases of mild intellectual disability is mixed (e.g. Polloway, 1985; Foreman, 1996). Many studies of inclusion suffer from methodological problems and many just feature briefly an experimental environment (Lloyd, Wilton & Townsend, 2000). However, Lloyd et al conducted an interesting naturalistic study in New Zealand of six children who were near the borderline of mild intellectual disability. They found that integration was not successful. After seven months, all children had made poor academic progress and their classmates poorly accepted five socially. Their teachers reported being concerned about their lack of progress but stated that they had enough problems coping with the needs of all the other children. Much more research needs to be done on the advantages and disadvantages of inclusion.

<u>When to teach</u>

Education of persons with an intellectual disability may begin well before the child reaches school age or even shortly after birth. This "early intervention" involves providing services and supports to children with a disability or who are at risk of developing one. In some Western nations, government or private organisations provide very early intervention services for parents. For example, in NSW, a representative of the Down Syndrome Association of NSW will contact the parents of a newborn child with Down syndrome to provide information about the syndrome and the services available. NSW also has an

early intervention referral service listed in the phone book and the NSW education department provides various early intervention services (Special Education Handbook for Schools, 1998).

Early intervention services may include not just education but also health care, social services and family supports. Hickson, Blackman and Reis (1995) list two main goals for early intervention. The first is to minimise or reverse (where possible) the impact of the delays or deficits in normal cognitive development on later school performance. The second is to support family efforts to achieve desired intellectual, vocational and social outcomes (P. 223). For individuals with a more severe disability, early intervention might aim to reduce delays in reaching significant developmental and cognitive milestones, such as walking or talking. This is often achieved by participating in infant stimulation programs directed by professionals and continued at home by parents who are trained by the professionals.

Thus, early intervention efforts can take various forms. For example, a baby born with Down syndrome may undergo physical therapy to strengthen muscles, as muscle tone is usually poor. Normal infant development is almost always delayed, resulting in increased time to learn to sit up, crawl and walk. Physical therapy can shorten the delay. Early educational programs may provide extra stimulation to promote learning. The well-known Head Start program in the United States aimed to prevent mild intellectual disability due to

growing up in an impoverished environment that had too little stimulation (Spitz, 1986).

Family-centred early intervention considers the needs of the family as well as the child. The focus is on enabling and empowering the family (Dunst, Trivett & Deal, 1988). Such programs are comprehensive and outcome based (McDonnell & Hardman, 1988). The curriculum is individually based and concerned with needs of both the child and the family (Beirne-Smith et al, 1998).

Early intervention programs aimed at preventing mild intellectual disability have been many. How effective are such early intervention programs aimed at improving IQ? Some researchers have been pessimistic about prospects of preventing or "curing" intellectual disability (e.g. Spitz, 1986), and there have been concerns that many intervention programs achieve apparent success only by teaching participants how to do IQ tests. However, some evidence suggests that early intervention programs may increase IQ scores and cognitive functioning (Forness, Kavale, Blum & Lloyd, 1997; Hickson et al, 1995). Unfortunately, these initial gains tend to diminish by the time the child enters school (Casto & Mastropieri, 1986). Some evidence suggests that very intensive early intervention programs may yield strong and sustained gains in IQ scores (e.g. Ramey & Ramey, 1999). A particularly intensive program called the "Abecedarian Project" was carried out by Craig Ramey and his

colleagues (e.g. Campbell, Ramey, Pungello, Sparling & Miller-Johnson, 2002). It involved extensive daily stimulation sessions and dietary supplements for at-risk children, with some success. At age 21, participants scored higher on IQ tests and had attained more years of education than control participants (Campbell et al, 2002).

<u>The school years</u>

As mentioned above, school education for persons with an intellectual disability may have a number of goals. Schools typically provide an "individualised education plan" (IEP) for students with an intellectual disability, as well as for all other special education students (e.g. Ashman & Elkins, 2005). The IEP's exact form varies across school systems, but usually has a statement of annual educational goals, how to reach them, and criteria to determine whether they have been met.

Persons with an intellectual disability need to be prepared for the work force but often their actual employment rates are poor. In the United States, Waldes, Williamson and Wagner (1990) found that only 20% of their participants in a longitudinal study were employed either part time or full time. For females, employment rates are particularly poor (Chadsey-Rusch, Rusch, & O'Reilly, 1991; Welman, Moon, Everson, Wood & Barcus, 1988). To foster better employment rates in the United States, a federal law (Public Law 105-17) was passed which required a transition to the working world statement

including goals, needs and services to be present in a student's IEP from the age of 14 years onwards. Further instruction in self-determination (self-direction) has been recommended to enhance employment prospects (Wehmeyer & Metzler, 1995) and success in living in the community (McGrew, Johnson & Bruininks, 1994).

Adult Education

Education may continue for life. Adult education for persons with an intellectual disability may involve specific instruction in areas such as using public transportation, using money, handling finances, living independently, and improving social behaviour. In Australia, Technical and Further Education (TAFE) courses, which teach specific vocational skills to persons who have left high school, are a possibility for persons with an intellectual disability. For instance, several workers at Sunnyfield Homes, where the present study was carried out, regularly attend TAFE classes. They are excused from work at Sunnyfield and are given transport to classes.

How to teach: methods

Educational methods vary greatly. There are lectures, discussions, textbooks, discovery learning procedures, and e-learning methods, for example. Learners also can have greatly varying learning styles (e.g. Howard, 1995; P 160-162) and preferences for using one learning method over another.

A fundamental question about education is which methods work best for which students in which circumstances. This question can be asked about education for persons with an intellectual disability. Gargiulo (2003) notes that methods that are often used effectively with students who have an intellectual ability are those that work well with all pupils. Gargiulo (2003, P. 175-180) provides a good overview of some major methods, and the brief description below largely is drawn from that work.

There has been something of a shift from use of behaviourally-based methods, which might emphasise teaching specific responses and the rote learning of facts and procedures, to a more cognitive approach, emphasising the development of conceptual understanding and reasoning and strategies. Either approach suggests different educational goals and methods (e.g. Howard, 1995, P 189-198). The methods described below draw from both approaches, however.

Task analysis

This method derives partly from the behavioural approach. A complex task or behaviour is broken down into smaller components and these are taught in sequence. Alberto and Troutman (1999) list some major aspects. These include selecting manageable goals, identifying prerequisite skills for learning a task, identifying needed materials to perform the task, and having students observe a competent person perform the task. LaCampagne and Cipani (1987)

successfully used a task analysis approach to teach some banking skills to adults with a mild to moderate intellectual disability.

Cooperative learning

Non-disabled children often learn effectively in peer groups and this technique involves use of this practice. Learners actively work together in small, varied groups to complete some activity, perhaps supported by the teacher (Slavin, 1990).

Unit approach

The unit approach derives from Ingram (1935) and once was used widely in the United States. The basic idea is to divide the curriculum into specific living skill content areas, such as health and money management. Within each such unit, teachers link specific skills (such as reading and arithmetic) to the unit under study. The subject is taught as a whole entity, crossing the usual divisions of reading, math, writing, and job skills. Gargiulo (2003) gives the example of a student being asked to write a letter to a potential employer or to compute his or her future wages. The aim is that students will connect the academic instruction to situations in the real world.

Scaffolding

Persons with an intellectual disability typically are passive learners. The goal of scaffolding is to provide much early support in the early stages of learning and then gradually remove the supports (the scaffolds) as learner

competence increases. Scaffolding is useful for the intellectually disabled in that it provides needed supports at first, adds new information in logical sequence, and builds on the learner's knowledge base. The teacher begins with what the student already knows and tries to link new information with that existing knowledge.

Friend and Bursuck (1999) give the following description of a learning procedure involving scaffolding. The teacher introduces a strategy and models it. The strategy is presented one step at a time, with guided practice being provided. Varying contexts are provided for the student to practice the strategy, first with the teacher and then in small groups. The teacher provides feedback and check lists for students to self-evaluate. Then each student is required to use the strategy independently, with support gradually lessening as he or she improves in performance. Finally, the student undergoes independent practice, applying the newly learned skill to a new situation.

Chapter Three

WORK, LEISURE AND RETIREMENT IN GENERAL

Having now examined intellectual disability and its educational aspects, this thesis can now look at work, leisure and retirement in general. The main purpose of doing so is to give a better context to the discussion of this topic with persons with an intellectual disability, covered in the next chapter.

Work, leisure and retirement are major parts of human life. Work, of course, is essential to maintain society and Westerners tend to frown upon any shirkers, but also it can have many benefits for individuals (Appelbaum, 1992). Leisure is essential to help relieve stress, foster social relationships, improve physical and mental health, and enrich life (Caldwell, 1990; Iso-Ahola & Mannell, 2004). Finally, there is retirement; leaving paid employment entirely, perhaps necessitated by declining physical capacity.

Adequately preparing for and balancing these aspects of life are necessary for well-being. This section will look at each of these domains in general, and how they have altered in the last few decades for much of the Western population. This discussion is important background material for understanding ways in which to deal with these domains in persons with an intellectual disability, examined later in this thesis. Not all the material covered in this

section is directly relevant to intellectual disability at the present time, but may become relevant later and so is considered in some detail here.

<u>Work</u>

Work has been viewed in different ways. In Western society, the Protestant work ethic (the idea that work is good in itself and idleness is reprehensible) is deeply ingrained and provides a key motivation for workers (Parker, 1975; Edwards, 1995). However, before the work ethic's development by John Calvin, work was viewed mainly as an unfortunate necessity of life, not a good thing in itself. In the Bible, the need to work was treated as part of the punishment for the fall from the Garden of Eden. Today, the work ethic still may not take strong hold in some workers, who live just for weekends. The attitude is expressed in the anonymous saying "Work is the rent we pay on life". Critcher and Bramham (2004) note, "The devil still makes work".

However, work can have many benefits. One benefit of paid work of course is the pay-cheque, which enables not just subsistence but desired leisure activities. Leisure time may be valued more when a person is in paid employment, partly because he or she has less free time. This feeling is well summarised by the anonymous saying "The problem with being unemployed is that you never get a day off". Work may provide satisfaction in itself through social interactions, providing contacts outside the family (Jahoda, 1982). Work may provide social status (Appelbaum, 1992) and, as Salaman (1974) notes,

may help define individual identity (e.g. I am a miner, I am an academic, I am a priest). "What work do you do?" is commonly asked to locate socially an individual. Other benefits may include mental stimulation for some workers and the opportunity to learn, develop and exercise skills. Appelbaum (1992) summarised the centrality of work in Western society as follows:

"Work is like the spine which structures the way people live, how they make contact with material and social reality, and how they achieve status and self-esteem… Work is basic to the human condition, to the creation of the human environment, and to the context of human relationships." (Appelbaum, 1992, p. ix).

However, extent of work satisfaction itself may depend on many factors; the type of work done (e.g. coal mining versus academic work), employer policies and management styles (Scott, 1994), and organisational climate (Shadur, 1999). Low-end, poorly paid jobs in which a worker has little or no control over his or her activities are more likely to yield less satisfaction than highly skilled jobs with much autonomy.

Types of work

Some writers treat paid work as the only type, but of course there are other kinds, such as daily chores and unpaid childcare. Paid jobs themselves come in various types; full- or part-time, permanent or term-limited, casual or

not, renumerated by time spent or by piece work, done in an office or at home, and so on.

A useful distinction is between paid and volunteer work. The latter sometimes is considered as a leisure activity or perhaps as a "serious leisure" activity (like a hobby such as collecting antiques) rather than a "casual leisure" activity such as watching television sitcoms (e.g. Stebbins, 2004). Volunteer work may allow many satisfactions, giving a sense of purpose and allowing a person to explore new interests and to gain new social contacts.

Preparation for work

Much formal schooling involves preparation for entering the workforce. This preparation can range from teaching basic skills such as reading and writing, teaching specific vocational skills such as welding, and teaching the "hidden curriculum"; the existence of rules and regulations, the value of punctuality, obedience to authority, and so on.

Aspects of this preparation have changed greatly in the last few decades in industrialised nations, along with changes in national economies and the globalising world economy. In Australia from 1945, for example, most persons completed primary and a few years of high school, and then obtained a job in an organisation for which they expected to work for life. At age 65 they would retire and live a few more years on a pension. Now, most students complete

high school and more attend university than used to be the case. Many undertake post-high school vocational training (Clitheroe, 2003, P. 14). In addition, many persons change professions at least once during their working life, often taking breaks from formal employment to return to school for further training for a new field (Long, 2004a). This change can be their own choice or due to their job being made redundant. Advances in technology have made many types of occupation obsolete, and many individuals must retrain. In rapidly changing fields such as information technology, workers must continually retrain just to keep their current job.

Changes in working life

Working life has altered in industrial nations in recent times (Zuzanek, 2004). The work week has lengthened in the United States (Schor, 1992). In Australia, a number of changes have occurred. Unskilled jobs are disappearing and more people work in white-collar jobs (Clitheroe, 2003). Workers tend to change jobs more often and may have little or no loyalty to an employer. The latter also may have little loyalty in return, readily making employees redundant when no longer useful. Full-time, permanent jobs are harder to get as employment becomes increasingly casual, with poor benefits. Many workers feel they have to work harder and longer hours and some employees complain of increasing unpaid hours.

The above changes, the increasing technological demands of many jobs, and the need for many working women to juggle work commitments and child care are leading to increasing reports of stress (Zuzanek, 2004). Verespej (2000) found that 46% of the workers he studied (at the Kensington Technical Group) reported increased levels of work stress in the past year, partly due to use of technology (voice and e-mail). Some argue that the price for prosperity in the global economy is more job stress and burnout (Minter, 1999). This increased stress may affect enjoyment of leisure time, as discussed in the next section.

Increased working hours and increased stress have sparked a number of responses in overworked workers, discussion of which is a popular media staple. For instance, Long (2004a) notes that some workers take long breaks from their regular jobs to pursue other interests. The latter may include a different job, more time spent with family or further training, with financial plans made when working to cover the costs for this period. Some employers may allow employees the opportunity to take long breaks to pursue other interests.

Some stressed workers have made responses that blur the lines between work, leisure and retirement. Some examples are as follows. "Downshifting" is changing from a fast-paced, hard-working lifestyle to a less stressful one; for instance, abandoning a high-powered, lucrative but stressful job for a more

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interesting but less lucrative one or for a job with many fewer hours. Downshifting can mean scaling down one's standard of living and/or moving from the city to a rural area (also sometimes called "voluntary simplicity" or "making a sea change"). It can be popular. Surveys by Hamilton (2003) and Schor (1998) found that many adults were reducing working hours, taking lower paying jobs, changing careers, ceasing paid work outside the home and/or starting their own businesses. The persons making such life changes cited such motivations as wanting to spend more time with their family, attain a more balanced and healthy lifestyle, gain more control over their lives, achieve greater personal fulfilment, lead a less materialistic life style, and be more environmentally friendly.

Such a change can work well. Tan (2004) surveyed sea changers. Dominant motivations in their previous careers had included getting ahead, getting more skilled, and becoming more economically secure. In the age range of the 30s to the 50s, the work motivation had changed towards being more balanced, more authentic (being true to who they are), and having more autonomy. However, many cited other reasons for making a change such as longer work hours at their previous job, increased work pressures, organisation/cultural change, unpleasant incidents at work and incongruity between their organisation's values and their personal values. Regardless of the motivation for the change, many sea changers were happier after it.

<u>Leisure</u>

The term "leisure" has been defined in various ways. A widely used definition is a residual one; "… time which is not occupied by paid work, unpaid work or personal chores or obligations" (Haworth & Veal, 2004, p. 1). However, it often is difficult to distinguish between work and leisure activities. For instance, a given activity (e.g. repairing automobiles or playing tennis) may be work for one person but leisure for another.

Leisure has many benefits and is important in quality of life (Lloyd & Audl, 2002). Participating in physically active recreational activities such as swimming may benefit health, help gain social contacts, and raise an individual's feelings of independence and self-worth (Jobling, 1997). Leisure education programs also may increase well-being (Searle, Mahon, Iso-Ahola, Sdrolias, & Van Dyck, 1998).

Surveys suggest that people engage in a wide range of leisure activities. The general rise in real incomes in Western nations in the last few decades and decreasing air travel costs have allowed many more activities for many, such as foreign travel and adventure travel.

Many variables may affect which leisure activities are favoured and how often an individual participates in them, such as culture, time and facilities available, friends and relatives willing to participate, and transport available. Also, there is some evidence that persons with higher socio-economic status

tend to take part in a wider range of leisure activities, perhaps partly because they have more money to do so (Veal, 2004)

Leisure interests and activities also may change over the life cycle, as other things change, such as physical capacity, mental acuity and financial resources. The avid partygoer at age 20 may be a stay-at-home stamp collector and television watcher at age 30. In the past, younger people typically have been much more physically active, and there is increasing concern nowadays that many youngsters get too little exercise because they stay glued to computer games and television sets.

In Australia, leisure has had a hallowed role, quite unlike that in very strongly work-oriented cultures such as Japan in the 1960s. Australians value their leisure so much that some observers have dubbed Australia a "recreation society" (e.g. Mosler, 2002), in which leisure time is predominant and work is perceived as a necessary evil. However, the economic changes mentioned earlier may be creating a more work-oriented Australian society. Australian leisure life tends to revolve around sports, socialising in barbecues and pubs, and going to the beach. The warm climate also allows many year-round outdoor activities, such as outdoor sports, which are very popular even if many individuals only are spectators.

Some Australians have favoured physical exercise (Kirk, 1996). Two government programs ("Life-Be in it" in the 1980s and "Active Australia") in recent years have tried to encourage more physical activities in leisure time.

Relationships between work and leisure

Work and leisure may be linked in a variety of ways (e.g. Veal, 2004). For instance, if a worker is extremely tired and/or stressed from long, hard workdays, he or she may shun all active leisure pursuits during the week, just watching television before falling asleep. Severe alienation from work may make a person angry and frustrated in leisure hours as well. Very long, irregular or very unsociable work hours from shift work may cut into leisure lives (Long, 2004b). Irregular hours may mean difficulty in favoured leisure pursuits because facilities are closed or because friends and relatives work different hours. Pocock, Van Wanrooy, Strazzari and Bridge (2001) document negative effects on health, family and leisure lives of irregular imposition of working hours by Australian employers.

Job status may affect leisure time and leisure activities (Oliver, Zarb, Silver, Moore, & Sainsbury, 1988). Leisure activities usually require money and the unemployed may suffer accordingly. Finally, work mates often are leisure mates as well (Salaman, 1974; Barnes, 1991). For example, coal miners who work together may spend their leisure hours socialising together.

Because of these interactions, work and leisure need to be balanced for well-being.

<u>Retirement</u>

Retirement is defined as the cessation of formal, paid employment. However, the boundaries between being in the workforce and having retired can be murky. Some workers may retire in stages, with a shift to part time work and then perhaps to a few hours a month as a consultant to the former employer. Even after formally retiring from paid work, an academic may maintain a university office and participate in much the same teaching and research activities, which now are unpaid. Even a "downshift" from an 80-hour a week job to a paid 40-hour a week job may stretch the categories.

<u>Adjustment to retirement</u>

What makes for a satisfactory adjustment to retirement? This topic has been extensively researched and various manuals for successful retirement are available (e.g. Schlossberg, 2004) as well as popular magazines for the retired.

One might expect that such factors as financial security, good health, ample leisure activities, and strong social connections would be particularly important, as evidence indeed suggests (e.g. Reitzes & Mutran, 2004). Another factor may be whether retirement comes predictably and is welcomed. Some persons retire happily and thankfully, many doing so voluntarily earlier than age 65. Those in dangerous and difficult occupations, such as coal mining, may be

more likely to welcome retirement. Manual workers may feel physically worn out by their 50s and find hard physical labour painful and difficult, for example, or dislike the lack of autonomy on the job (e.g. Blekesaune & Solem, 2005). At the other extreme, those in pleasant occupations such as university teaching may not be happy to retire.

However, retirement may be unwelcome, abrupt and unplanned. It may be forced by poor health, redundancy, or employer age policies. If retirement is unexpected and a person's sense of identity largely derives from the job, the resulting lengthy leisure hours, and less cash may lead to depression. Some retirees find life difficult after a few months (Van Solinge & Henkens, 2005). Even if financial provisions have been met, some find that they have lost their sense of usefulness and worth, which derived from their work. Work may have occupied a very salient part of their lives. Some persons have developed no interests outside of work, are bored in retirement, and have a lack of purpose in their lives (Grossin, 1986). Some evidence suggests that many persons prefer to remain employed in some ways even after official retirement; such as in part time work (e.g. Lim, 2003).

One way to determine factors that might make for a satisfactory retirement is to look what factors make for general life satisfaction, which could then be carried on into retirement. Some indications are from a longitudinal study by Vaillant (2002), which began in 1932 and followed the life course of

teenagers into their early eighties. Vaillant made *s*ix major conclusions about determinants of well-being. First, happiness is not determined by negative life events, but rather by the people in a person's life. Second, relationships are very important. Third, if an individual has a good marriage at age 50, this is a good predictor of well-being by age 80. Fourth, alcohol abuse negatively impacts on happiness, mainly because of the social consequences. Fifth, being able to play and create and make younger friends was important. Finally, subjective good health is more important than objective good health.

Longhurst (2000) reported the findings of "Retire 2000", an Australian research program examining 100 male and 100 female retirees from rural and urban areas. The aim of the research was "to differentiate the behaviours of those participants of the program who had adjusted well to retirement from those for whom retirement was a less happy experience". Adjustment was related to the levels of retirement-related anxiety, retirement-related depression, levels of retirement-related stress, and levels of comparative global satisfaction (defined as the comparison of life satisfaction before and after retirement, Longhurst, 2000, P. 13). Eight factors enhanced retirement satisfaction. These were:

1. The individual retired voluntarily.

2. The individual could retire at age 55 or younger.

3. The individual had financial independence.

4. The individual spent at least five hours a week in purposeful activities.

5. The individual had someone to rely on for emotional support.

6. The individual maintained health through exercise, a balanced diet and regular medical checkups.

7. The individual had sound financial planning and planning for an active lifestyle.

8. The individual had received pre-retirement advice and/or education.

These general findings were corroborated by informal readership surveys conducted by the popular magazine "Your Life, Your Retirement" (Fallick, 2004, P. 189-190). This is a non-academic study of course, with less credibility due to sampling and other difficulties, but does give some interesting information. Over five years, readers were asked, "What are the key ingredients for a happy second life?" and then they rated (on a six point scale) the factors of health, purpose, financial security, a variety of activities, good relationships, and work.

Some key findings were that growing older was not always perceived as negative. While some physical and psychological functions may decline, there are many compensating factors. Staying connected with the wider world was seen as important, as was being able to "give back" to grandchildren, to other family, to the community, and to the environment. Physical and mental well-being were seen as inextricably intertwined. Financial security was seen as

important, as was keeping mentally active and being able to travel. Retirees felt that they need good social contacts. To the latter end, volunteer work could be very rewarding.

Retirement trends and issues

Issues concerning retirement are particularly important nowadays because aspects of retirement and retirement planning have changed greatly in Western societies, for several reasons. First, people on average are retiring much earlier than the stipulated 65 years old, voluntarily or involuntarily. Clitheroe (2003) found that Australians on average are retiring much earlier than age 60, with funding coming from their own investments. Some researchers predict that eventually retirement years will exceed working years (e.g. Grossin, 1986).

Second, people on average are living well beyond age 65 and may need to fund retirement for much longer than in the past (Riley, 2001). Indeed, when in 1889 in Prussia, Otto von Bismarck first introduced government-paid age pensions for those aged 70 (later reduced to age 65), very few persons lived long enough to ever collect one. Life expectancy was only about 45 years (Riley, 2001). In the United States, the Social Security program was established in the 1930s to fund retirement at 65, an age that most Americans were not expected to live to or much beyond.

Third, in industrial nations, women are having fewer children, and birth rates in many nations have fallen well below the replacement level of 2.1 per woman. In Australia, the rate is about 1.7 children per woman. This decline is especially a problem in Italy, Spain and Japan. Japan has a median population age of over 42 years old and a birth rate well below population replacement level. A concern is that eventually there will be too few workers to support an increasing proportion of retirees.

Governments are looking at various possible remedies. One is to raise the age of retirement and to ban employer compulsory retirement policies. In NSW, compulsory retirement at age 65 was made illegal for most workers (Some such as police officers, still have compulsory retirement ages). However, employers may implement age policies through other means, such as redundancy. A second possible remedy is to reduce social security benefits or to make them harder to get. A third is to encourage workers to save and invest more for their own retirement rather than expecting to live on a government pension. The Australian government has introduced compulsory superannuation for all workers where employers must contribute 9% of salary to each worker's retirement fund. A fourth is to encourage more staged retirements; e.g. a shift to part-time work, and then slowly decreasing its extent. In 2005, the Australian Government aimed to encourage staged retirement by allowing individuals to

access their superannuation funds before having to retire from all work (Fenech, 2005).

These trends suggest that workers need to think about and plan for their retirement very early. Otherwise, retirement years may be impoverished and unpleasant. Also, a spouse may need to be considered in planning, as each spouse may experience retirement differently (Van Solinge & Henkens, 2005).

Chapter 4

WORK, LEISURE AND RETIREMENT WITH PERSONS WITH AN

INTELLECTUAL DISABILITY

This thesis can now consider work, leisure and retirement in the lives of persons with an intellectual disability. There are many similarities with among people in the general population. Some persons with an intellectual disability do hold jobs, and gain work satisfaction, social contacts and income from work. They also have active and satisfactory leisure lives. They may face the same problem of balancing work and leisure. However, their retirement is a particular concern because many are living much longer. Typically, the disabled face many more challenges in these domains, and education to improve their functioning is becoming increasingly important.

Each domain is examined in turn.

Work

Preparation for work

Preparation for work for persons with an intellectual disability was not a great societal concern in the first half of the twentieth century, because so many did not survive to adulthood. Relatives or institutions provided day care and any preparation for work and public sector education was limited. However, societal

attitudes changed and eventually laws (such as PL94-142 in the United States) mandated an education for all children, regardless of disability.

Lack of education placed another limitation on what work persons with an intellectual disability could do, along with their cognitive and emotional limitations. More recently, increased educational opportunities mean that many may have a better chance of entering the work force. For instance, in NSW, from Year Seven, schools now teach job skills to persons with an intellectual disability, including punctuality, appropriate social interaction skills and specific vocational skills (Special Education Handbook for Schools, 1998). Schools also may arrange work experience programs, allowing students to work at a specific job (such as cleaning) at an actual work site and to try out various jobs to see which type suits best. Work experience typically is unpaid but school credit is gained and sometimes the student may get a paid job at the same site after finishing school. For example, Sunnyfield Homes has a sheltered workshop that caters to many high school students on work experience. Some eventually work at Sunnyfield after leaving school.

Working life

Because of limited education and their cognitive deficits, individuals with an intellectual disability who do hold jobs typically do work which has limited intellectual demands, such as gardening, assembly, and packaging. The work may provide a small income, some social contact and the opportunity to

contribute to society. In complex industrial societies, finding suitable jobs for those with an intellectual disability who can work may become increasingly difficult because unskilled jobs are disappearing. Jobs increasingly require computer skills, which themselves may need continual updating, for example.

There are several work options, which involve varying levels of support from others. These were briefly mentioned earlier, and now can be described in more detail. First, <u>competitive employment</u> means holding a normal job, either part time or full time, with the same pay and benefits as non-disabled workers. This would seem the most desirable option for many, though some do not have the necessary job skills to compete effectively on the job market. Another common problem is that an individual may hold a job but fail at it, which sometimes may occur not because of poor vocational skill levels or poor job performance but due to lack of interpersonal skills (e.g. Butterworth & Strauch, 1994; McGuire, 1999). An easier form is <u>supported employment</u>, in which the individual is in competitive employment but also has a job coach who provides on-the-job training and advice and gradually decreases that support (e.g. Mank, Cioffi & Yovanoff, 2003). The job coach usually first locates the job and matches employer needs to the worker' s abilities and also helps train such skills as punctuality, appropriate dress, and getting along with fellow workers and the supervisor. This option can benefit both employee and employer (Beirne-Smith et al, 1998; Test, Carver, Ewers, Hadda, & Person, 2000). One

drawback is that the worker may become too dependent on the job coach (Lagomarcino, Hughes & Rusch, 1989). Research has found that this method is cost-effective (Beirne-Smith et al, 1998), and can work better for training purposes than a sheltered workshop (Goldberg, McLean, La Vigne, Fratobillo & Sullivan, 1990).

Second, a sheltered workshop involves working with close supervision and with more limited tasks, and typically with less than full time working hours. In general, large sheltered workshop facilities provide work in a segregated environment, performing contract jobs such as refurbishing head-phones for an airline. The work typically is repetitive and requires little skill. Sheltered workshops may provide a variety of jobs within the facility. Criticisms of sheltered workshops include low wages for the workers, a segregated work setting, absence of meaningful training and failure to move clients to competitive employment (Shuster, 1990; Wehman, Moon, Everson, Wood, & Barcus (1988).

Third, a day program involves only work and training that an individual can cope with. This option typically is for those with highest support needs. This training eventually may lead to work in a sheltered workshop, but some participants remain in a day program for their entire adult lives. NSW provides day programs that continue for only a few years after formal education. In this program the students learn individual skills such as independent self-care needs,

fixing a simple meal, and performing specific tasks that will be needed on the job. However, day programs in NSW may have long waiting lists for entry, with priority going to those with greatest support needs, such as those lacking carers.

However, many persons with an intellectual disability never work at all. For instance, a longitudinal study in the United States by Valdes, Williamson and Wagner (1990) of 436 young adults found that half were unemployed and only 20% had either full time or part time competitive employment.

In Australia, the "Disability Data Briefing" of March 2000 (Australian Institute of Health and Welfare, 2000) gives numbers of Commonwealth-funded disability services broken down by state and territory. A total of 17,735 persons with a disability were receiving employment services in Australia around that time, though this figure includes physical disabilities. NSW had the highest number in open employment, in supported employment, in combined open and supported employment and in employment "other/not stated", with 330 individuals. The total for these categories for all six states and the Northern Territory was 857. However, these data have limitations. For instance, many older persons with an intellectual disability over the age of 40 may not be tallied in such counts. They are unknown to government disability services and may be unaware of available benefits and programs (Buys & Rushworth, 1997).

<u>Leisure</u>

As mentioned earlier, persons with an intellectual disability have leisure needs just as the general population does. Those who work need to balance their work and leisure lives as well. They should gain such typical benefits as stress reduction, a sense of autonomy, and increased well-being and life satisfaction from leisure (Caldwell & Gilbert, 1990; Heller, Miller, Hsieh, & Sterns, 2000). Indeed, researchers suggest that adding more leisure activities can improve the well-being of individuals with an intellectual disability. For instance, Gaudet and Dattilo (1994) found that recreation activities provided institutionalised participants with more of a sense of control over their lives. McGuire and Chicoine (1999) found that individuals with an intellectual disability who live in community settings and stay active are more likely to maintain their skills and moderate the ageing process. They recommended maintaining a high level of social and recreational activities. And, even for those who do not work, "serious leisure" as a main activity has been proposed as an alternative, or as a way to train work skills in a non-threatening and enjoyable way (Patterson, 1997).

Relatively little research has examined how adults with an intellectual disability view leisure but a number of studies have looked at their actual leisure activities. Here are some examples. Buttimer and Tierney (2005) looked at the leisure activities of 34 students with an intellectual disability who were attending a full-time special school. Their leisure activities were not very

satisfactory. Most of their common leisure activities were solitary and passive. Several barriers to better leisure activities were noted, such as poor access to facilities.

Benz and McAllister (1990) studied adults in Oregon, aged from 35 years upwards. Many participated in a day work program, and 88% reported being satisfied with their leisure activities. Satisfaction with daily activities for the group not in a day program was not given. However, 19% of those aged 35 to 54 and 35% of those older than 55 had no structured day activities at all. They watched television, did household chores, participated in hobbies, visited friends, and participated in sports, games, shopping and walking and went to movies. Over half stated that they would like to participate in additional leisure activities, but reported such barriers as lack of transport and other persons to go out with. Benz and McAllister (1990) advocated continuing leisure education for older adults with an intellectual disability.

Physical exercise is an important leisure activity, with many variants. Medlen (2001) looked at lifestyle attitudes and practices of nutrition and exercise with 137 individuals with Down syndrome in the United States. The participants ranged in age from 15 to 45 years old, with an average age of 27. Most (80%) reported having done some form of physical activity on the day of the survey and out of these, 95% stated that they exercised regularly. This percentage was much higher than the reported national average of 46% of all

Americans. The participants most often cited activity was dancing, closely followed by swimming and walking.

Ashman and Suttie (1995a) looked at social and community involvement of 446 older persons with an intellectual disability. Except for those living with their families, most made little use of social and recreational facilities or travelled independently. The authors suggested the need for more independence training to better prepare them for community activities.

Temple, Anderson and Walkley (2000) looked at the amount of healthy exercise that six participants received in a group home in Victoria. Some beneficial exercise was gained at work, such as gardening activities, but all got exercise while travelling to and from either work or a day program. Appropriate physical fitness levels could have been achieved by all six of the participants if they walked faster to their workplaces. Most people with an intellectual disability walk or use public transport, and Temple suggests more encouragement to walk for health reasons.

How may the leisure lives of individuals with an intellectual disability be improved? Meeting these leisure needs may be complicated by several factors. Many are housed in large residential institutions, often with poor opportunities for leisure. Staff may see the organised leisure activities that do exist as time fillers or as therapy for various deficits (Schleien & Ray, 1988). In Australia, Bigby (1998) found that many older persons surveyed were unhappy with their

leisure activities, performance of which often was hindered by lack of trained staff and finance. Even those in the community may have problems. Jobling (1997) suggested that mainstream sports and government programs such as "Life Be In It" and "Active Australia" should be equally available for persons with disabilities. However, Buys and Rushworth (1997) found local community services often had no specialised leisure programs for older adults with a disability. The main impediments to organising such programs were financial or staff constraints. In addition, it was found that a lack of linkages between disability and aged-related networks needed to be addressed to ensure adequate access and increased quality of life with age.

Another way is to improve their leisure lives is through education and training, described later.

Retirement

Concerns about retirement for persons with an intellectual disability were not considered a pressing issue until relatively recently. Relatively few lived long enough to actually retire (Janicki, 1990). In 1930, their life expectancy was only about 20 years, but this had risen greatly some decades later (Carter & Jancar, 1983). Because of lengthening life spans, governments and organisations that provide care and work opportunities for persons with an intellectual disability increasingly are concerned about future needs such as retirement programs (Bittles & Glasson, 2004). In Australia, policy on

retirement among persons with an intellectual disability still currently proceeds on a state-by-state basis (Bigby, 2002). Western Australia and Victoria have commissioned several studies to consider policy options (Gatter, 1996).

Needs of older persons with an intellectual disability

Ageing itself brings many changes and a variety of key issues concerning ageing and retirement arise with everyone. With age, loved ones may be lost, physical capacity reduced, roles changed, and impending mortality must be faced (Seltzer & Seltzer, 1985). Older persons with an intellectual disability face these and other issues. They also may be more susceptible to increasing social isolation as they outlive their relatives (Bigby, 2004), due to small social networks.

Health can be a major concern, with more obstacles than usual to effective health care (Bigby, 2002). Common health problems include incontinence, reduced mobility, hearing loss, arthritis, hypertension and cerebrovascular disease (Cooper, 1997a; 1997b, Cooper, 1998). A study by Durvasula, Beange, and Baker (2002) of 693 persons with an intellectual disability in northern Sydney found that they had higher death rates than the general population. The main cause of death was respiratory disease, with the greatest proportion occurring in those in the severe to profound range of disability. Studies by Lifshitz (2001; 2004) in Israel found that many persons with an intellectual disability in the sample studied have health problems by age

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40 years. Common ailments were diabetes and weight problems, derived from the participants' way of life and their eating habits and nutrition within residential institutions. Those who also had cerebral palsy were most affected by ageing, with declining physical functioning and some needing wheelchairs. Other ailments found were dental problems and visual and hearing impairments. Residents in the community also had many health problems. Lifshitz recommended that dieticians be employed, and that the individuals get education about what to expect in old age.

Mental health also may be a concern. Older persons with an intellectual disability may have two to four times the rate of psychiatric problems than the general population (Tor & Chiu, 2002). One reason for this is the high rate of dementia (Cooper, 1997b).

Another concern is suitable accommodation in retirement, over which many persons with an intellectual disability may have little choice (Ashman et al, 1995a). Many now are being housed in unsuitable aged care facilities, where staff are not trained to deal with intellectual disability (Bigby, 1992, 1998).

The Australian Institute of Health and Welfare (AIHW) reported a detailed study in 2002 of the needs of ageing people with a disability (AIHW, 2002). In general, these needs fall into three categories: biological, psychological, and social (AIHW, 2002, p. 44-45). The first category included possible needs for help in grooming and personal care, and in dealing with

sensory deficits (e.g. declining visual acuity), declining physical fitness, declining muscle tone and strength, declining mobility, and increasing likelihood of physical diseases. Psychological needs included possible aid in dealing with personality problems (some people develop personality problems as they age), motivation (due to lack of stimulation), changes in cognition (the need to keep the mind active), and personal control and choice (the need to have a range of options). Social needs included possible help in pre-retirement planning, social networking and role changes (to continue social contacts), and social effects of biological ageing (the need for transportation and mobility assistance).

For those with a lifelong intellectual disability, ageing was likely to bring additional problems (AIHW, 2002, P.46). Such individuals are more likely to have low levels of functional ability and to need residential care. They may need more help to use community services and facilities and to participate in community activities. Many have no spouse or children and many rely on aged parents or carers whom they may outlive. They are less likely to have good social networks outside the family or outside their residence, which is often a group home or hostel. [Indeed, persons with an intellectual disability are likely to have very small social networks. A study by Robertson, Emerson, Gregory, Hatton, Kessissoglou, Hallam and Linehan (2001) found that the median number of connections excluding staff to be two.] Communication skills are

often impaired and they may have difficulty expressing their needs. Sometimes they have low participation rates in formal and informal day activities and leisure programs, partly because few opportunities or choices are available. Also, long-term residential care may have reduced their capacity to engage in community activities. They are more likely to be dependent on disability pensions and to have no other retirement income. Finally, they are less likely to be home- owners (AIHW, 2002, P. 46).

However, all is not bleak. Older people with an intellectual disability may be fitter and more able than their younger disabled peers (Strauss & Zigman, 1996), because the more fit survive longer. An optimistic view of later life for the intellectually disabled was found in longitudinal research that noted positive changes occurring in old age among a cohort of formerly institutionalised inmates (Edgerton, 1994).

For the above needs, specialised services must be provided, which often currently do not exist. Ashman et al (1996) found that many older people with an intellectual disability mainly used specialist disability program services available to all age groups rather than community-based leisure facilities and programs for older people. The former may not be appropriate for persons with an intellectual disability. Many with a lifelong disability rely heavily on others to provide adequate and appropriate support, which can indirectly cause unintentional exclusion from community based services and activities (AIHW,

2002, P. 47). Inappropriate or intrusive behaviours of an individual may be unwelcome. In addition, the disabled are often perceived as being incompatible with present client groups. Some services do not provide a five-day, full time structured program. The location of services and limited personal cash may limit access as may lack of staff trained to support older adults with an intellectual disability (AIHW, 2002, P .47).

An interesting study by Bigby (2001) highlights some of these needs and concerns. She studied 62 females with an intellectual disability, aged from 55-87, with an average age of 66 years. All had left parental care after age 40 years. Most of the women had a strong informal network with a key informal support person. Some had also experienced multiple losses and been vulnerable to residential mobility and placement in inappropriate environments, such as aged-care services. Some suggestions from the study were as follows. Informal network members can act as their advocates and monitor the quality of service provided for them. Clients need a full range of primary care, day activity and leisure options. Finally, services should provide optimal skill maintenance and development and stimulate leisure and social opportunities appropriate to each individual's rate of ageing (Bigby, 2001).

Bigby (2002) suggested that a major priority should be a focus on healthy lifestyles and quality health and screening services to older people with an intellectual disability.

Retirement planning

Better retirement planning is, at present, a main concern. Persons with an intellectual disability need to plan better for their retirement years, aided perhaps by family and carers. Major concerns are the financial and leisure aspects of retirement, for which many persons with an intellectual disability get little or no education (e.g. Sutton, Sterns, & Schwartz Park, 1993). Bigby (1998) found that many such retired persons were unhappy with their leisure activities, performance of which often was hindered by lack of trained staff and finance.

Some researchers have argued that retirement planning should start with the views of affected individuals. For instance, Bigby (2004, P. 59) stated,

"The collective voices of people with an intellectual disability, their views on ageing, how they would like to be supported to lead a better quality of life, and what they regard as successful ageing are major omissions from the body of research in this field."

Relatively little is known about how older adults with an intellectual disability or members of their social network view later life, their options, and how to plan for this time (Mahon & Goatcher, 1999). Some research does suggest that some may fear retirement, due to its implied loss of meaningful activity, friendships and social contact (Ashman, Suttie & Bramley, 1995b;

Bigby, 2001; Hand & Reid, 1989; Sutton et al, 1993; Erickson, Krauss & Selzer, 1989).

Another complication is that persons with an intellectual disability have been in various forms of housing and work arrangements. For instance, an individual in a day program may have different needs than one in the work force. Bigby (2004) found that those who had been in a day program need continuing support adapted to their changing needs for day support, rather than a fundamentally different day program. Some issues concern how to reduce the intensity of the day program, hours of active programming, and how to change the program environment. Those in competitive or supported employment may need to choose when to retire (Bigby, 2004).

Some retirement and ageing programs

Various organisations and researchers have developed programs and various materials to help persons with an intellectual disability in retirement. A few examples are described here.

The Centre for Developmental Disability Studies, an Australian organisation, overviewed current programmes available to persons with an intellectual disability who were nearing retirement age. The Centre compiled a source book titled "Ageing in Place: Good Practice Sourcebook" (Dew & Griffin, 2002). One program profiled was the "Ability Options—Lifestyle Enhancement Program", whose operation commenced in 1996. It went from a

centre based day program to a community integration and access program. A variety of activities and courses of general interest are offered, particularly for people wanting to replace work with leisure activity. Major concerns are education and training in recreational programs, leisure programs (including home hobbies which the client can do at home), evening social programs offering a variety of activities with staff support, and community networking programs where clients are matched with mainstream activities.

A second program profiled is the "Ability Options—Lifestyle Options Development Program", which helps with retirement planning and implementation. The program involves first gradually reducing employment hours, first by one day per week, within an agreed upon time frame. That day's work is replaced with a TAFE program or a community activity. Then the TAFE program or community activity rises to two days a week or is replaced with a recreational option for the second day off. The process continues slowly until the client is fully retired.

The Sunnyfield organisation is concerned about developing programs to cater for the needs of its older clients (Gilchrist, 2003). At present, seven Sunnyfield accommodation residents are retired, and in the next ten years, another 19 residents are expected to retire. One issue is how to provide the same level of aged care for members currently living in the family home as those already in Sunnyfield accommodation. A second is how to provide additional

(non-employment) day care needed by retired Accommodation Service users in the next 10 years. A third is how to provide for special aged care needs, for example dementia, for the rising number of retirees. A fourth is how to maintain persons outside residential institutions for as long as possible.

One guiding principle is that persons with an intellectual disability take longer to adjust to changes like retirement, and a sudden cessation of work can cause great problems for them. So, Sunnyfield clients retire gradually, starting with just one day a week.

Chapter 5

EDUCATION FOR WORK, LEISURE AND RETIREMENT IN PERSONS

WITH AN INTELLECTUAL DISABILITY

Earlier, this thesis examined some general educational efforts for persons with an intellectual disability. This section briefly looks at some specific educational efforts in the domains of work, leisure and retirement.

Work

Education for work and for improving work skills in persons with an intellectual disability has been mentioned in several places in this thesis already. Concerns have been, for example, preparation for the work force by training of necessary vocational and social skills. Researchers also have been concerned with other aspects of work; ensuring and gauging work satisfaction, examining work history, examining models of supported employment and various other aspects (e.g. Revell, Kregel, Wehman, & Bond, 2000; Test et al, 2000).

Leisure

Leisure enhances well-being and persons with an intellectual disability need satisfactory leisure lives (Heller et al, 2000). A variety of relevant studies have been carried out which involved education to prepare for better leisure lives. These have reported various benefits from leisure education such as positive changes in attitudes, greater leisure awareness, and increased initiation

of leisure activities with friends and increased self-determination (e.g. Stancliffe & Abery, 1997; Williams & Datillo, 1997; Bedini, Bullock & Driscoll, 1993; Heller, Hsieh, & Rimmer, 2004). McGuire and Chicoine (1999) argued that people with intellectual disabilities should be allowed both challenge and independence in their lives, but not at the risk of their own health and safety. Care must be taken in selecting appropriate leisure activities. Also, a major limitation for individuals with a severe intellectual disability in making their own choices was lack of verbal skills (Stancliffe & Abery, 1997). Many participants were non-verbal and could not identify or communicate their own preferences.

Relevant studies of leisure education mostly have involved organising activities and encouraging individuals to participate in them, perhaps with additional enabling training. Samples typically have been very small, partly because of the intensive training sometimes needed. Some studies have taught specific leisure skills, such as gardening or ordering a drink in a pub. Some have involved training more general skills, such as social skills, whose lack may be a barrier to a satisfactory leisure life. Here are some examples.

O'Reilly and Lancioni (2000), in Ireland, successfully taught four adults with an intellectual disability a skill which can be very useful in that nation. They were taught how to greet a bartender and then to order and then pay for a drink at the local pub.

Bambara and Ager (1992) instructed three individuals aged between 31 and 57 years old, who had a moderate intellectual disability, to schedule and perform their own leisure activities. New leisure activities also were introduced to them. All participants showed improved leisure lives and they continued the new leisure activities after the training.

Several studies have aimed to promote physical fitness and exercise skills to promote active leisure activities. Podgorski, Kessler, Cacia, Peterson, and Henderson (2004) trained 12 older adults at a day rehabilitation centre to exercise more. Most showed improved physical functioning, and the physical activity sessions remained a popular activity for them one year later. Mactavish and Searle (1992) educated 13 older adults in choice and performance of physical activities. They reported enhanced feelings of competence and increased self-esteem and that the participants continued the exercises. Lancioni and O'Reilly (1998) trained a group of young persons to carry out physical activities that they could do independently. The participants showed improved physical fitness and the authors also reported reduced "deviant behaviour" with them.

Gaudet and Dattilo (1994) taught six institutionalised individuals with an intellectual disability various gardening skills, using a prompting method. With training, all required fewer prompts to do gardening and increased their independence in performing the gardening activities. The authors also argued

that these recreational activities had the added benefit of providing an opportunity for the individuals to make their own choices.

Jobling, Moni, and Nolan (2000) used videos and discussions to train seven young adults with Down syndrome to understand emotions, relationships and friendships. Emotions, relationships and friendships may be difficult for them to understand, and the lack of understanding may lead to social isolation.

Mahon & Bullock (1992) devised a program called "The Decision Making in Leisure" Program (DML). It aimed to teach decision-making skills that might also be applied to various domains, such as choosing accommodation and type and place of work, as well their leisure activities. Four adolescents with an intellectual disability were trained and later showed increased levels of independent decision making in their free time and increased responses to leisure awareness questions.

Retirement

As mentioned, organisations for persons with disabilities are planning for many more older and retired persons with an intellectual disability, who, like the rest of the population, are living longer and retiring younger (Janicki, 1990; Sutton et al, 1993). Several studies have focused on training programs for later-life planning for adults with an intellectual disability. Heller et al (2000) designed and successfully taught a training program about later life planning issues called the "The Person Centred Planning for Later-Life Curriculum for

Persons with Mental Retardation". It taught how to make choices about current and possible future residence, work options and ideas, health and well-being, use of leisure time and recreation, use of formal and informal supports, and how to set goals and make action plans. Participants who participated in the training program made significantly more choices. However, undertaking the program did not influence life satisfaction for participants studied.

Mahon and Goatcher (1999) devised a leisure education based later life planning model and trained ten older persons with an intellectual disability with it. This program had three parts: 1) retirement and leisure awareness and decision-making, 2) planning alternative future of tomorrow, and 3) leisure initiation. Participants were encouraged to think about their possible futures and then to work backwards from those visions in small steps that could lead to the vision. The authors reported that many participants made changes to their lifestyles, consistent with plans made during the study, and had higher life and leisure satisfaction as a result. One area where the program was not effective was in decreasing constraints to leisure. The biggest constraint was money, and the program did not address saving for retirement. Money is a central issue in retirement and needs to be included in any retirement awareness/training, and the latter needs to be taught many years before actual retirement.

More research appears to be needed on retirement education for persons with an intellectual disability.

Chapter Six

APPLYING A CONCEPTUAL APPROACH TO EDUCATION

Having now examined intellectual disability and issues surrounding work, leisure and retirement, this thesis can now examine the field of concepts. A major aim of the present study is to apply a conceptual approach to the education of persons with an intellectual disability, and now the theoretical basis of this conceptual approach can be examined.

Education typically works best when it proceeds from an individual's existing knowledge base (Ausubel, 1968). An individual's existing knowledge largely is organised around <u>concepts,</u> a term which is defined below. An individual's concepts have a number of important functions, also described below.

There is no generally accepted theory of concepts but cognitive psychology has produced a number of firm generalisations (Murphy, 2002), which can be applied to education (Howard, 1987). This section examines some research on concepts and describes how a conceptual approach may improve educational interventions.

<u>What is a concept?</u>

Concepts are studied by a variety of disciplines; philosophy, artificial intelligence, linguistics, psychology and education, for instance. These disciplines tend to define the term "concept" in different ways, and researchers within a discipline may even use different definitions. A very useful cognitive psychology definition is used here (e.g. Smith & Medin, 1981; Howard, 1987; Murphy, 2002). A concept is defined as a mental representation of a category. A category is a set of things in the world and a concept is what an individual knows about the category. The concept mentally represents the category. This knowledge may include facts that allow instances to be categorised and facts that relate the concept to other concepts. For example, the category of fruit consists of such examples in the real world as specific apples, peaches and dates. A given individual's concept of fruit may include much knowledge; that they have seeds and usually are edible and grow on trees, for example. A given concept may have many aspects, including knowledge of connections to other concepts (e.g. food and plant) and emotions towards instances (Howard, 1995). Therefore, different individual's concepts may differ enormously. For example, a biologist or a cat breeder will typically have a much richer concept of cat than will most pet owners. The knowledge included in an individual's concept of cat may include knowledge of different breeds, typical cat behaviour, the concept's relations to other concepts (e.g. that a cat is a mammal and a life form) and an emotional component (e.g. that the individual likes cats).

Cognitive psychologists and educators also often use the related term "schema" (e.g. Howard, 1987; Sweller, 1999). One definition of "schema" is as a mental representation of a set of related categories. However, it often is difficult to distinguish between the terms "concept" and "schema", which often are used interchangeably (see Howard, 1987, Chapter 3 for an extended discussion). Therefore, only the term concept is used in this thesis. Finally, a "word" is a label for a concept or category, with usually an arbitrary relation to the concept except for such words as boom and hiss (Howard, 1987).

Some characteristics of and uses of categories and concepts

As mentioned, an individual's knowledge largely is organised around concepts. These concepts have many uses; making inferences, acquiring new knowledge, and making sense of the world, for example (Bruner, Goodnow, & Austin, 1956; Howard, 1987). Being able to categorise a novel stimulus allows an individual to bring existing knowledge to bear and understand it better and to suggest adaptive courses of action. For example, being able to accurately categorise a large life form as a dolphin or a shark allows a swimmer to behave adaptively; (e.g., perhaps exit the ocean immediately). Concept formation and use is critical in science (Solso, 1995; Howard, 1987).

Concepts mentally represent categories. Categories have boundaries that may be sometimes unclear and which different individuals may put in different

places (McCloskey & Glucksberg, 1978). For example, some persons may not include tomatoes and dates in the category of fruits, while biologists do.

Concepts also may develop (Skemp, 1979; Howard, 1987). Knowledge contained in them may alter; for instance by increasing or becoming more abstract. For example, a young child's concept of father may initially just encompass his or her own father, then a man who lives in a house with some children, and then much later be based on the abstract biological features. Keil and Batterman (1984) found that younger children tended to base concepts on surface features while older ones used more abstract features. For instance, younger ones saw an uncle as a man in his 20s or a museum just as something with dinosaur bones while older ones understood the definitions better.

An individual's concepts may be organised into larger structures such as taxonomies. In a taxonomy, concepts are organised by increasing abstractness and the relation linking concepts in adjacent levels is class inclusion. For example, a taxonomy of life forms may start with life form. Subsumed within it on the next level of abstraction are such concepts as plant and animal, themselves divisible. Animals can be divided into mammals, reptiles, birds, etc, and so on. A taxonomy may have a "basic level" of categorisation on which an individual typically operates (Murphy, 2002). For example, most people typically refer to certain animals on one level of abstraction (e.g. as dogs, cats and rabbits), although other levels of abstraction could be used. But, in most

circumstances it would sound strange to use levels other than the basic, for example by saying, "Here is my pet life form Fido" or "Here comes a black mammal".

Research issues about concepts

Different disciplines have focussed on different issues about concepts. Education, for example, particularly has been concerned with how concepts are learned and how they are best taught (e.g. Tennyson & Park, 1980). The latter issue is considered in more detail below. Cognitive psychology research in the last few decades has been concerned with a variety of issues, such as how concepts are acquired and how existing concepts may be affected by use and existing knowledge (e.g. Murphy, 2002).

Much research has been concerned with the issue of exactly what information individuals acquire when learning a concept, which then allows them to categorise instances and non-instances. The long-dominant theory dates back to the Ancient Greeks. It proposes that individuals learn a set of "defining features", common features that all members of a category share. These are singly necessary and jointly sufficient to categorise all instances. For example, the concept of square consists of such features as "plane, closed figure", "has four sides of equal length", and "has four internal right angles". This feature set is used to categorise new instances; simply by seeing if they have all the features. If a stimulus has them all, it is a square. If it lacks even one, it is not a

square. Other theories have been proposed; that concepts may consist of a prototype (a highly typical instance or an idealised instance) or of knowledge of exemplars, for instance (Smith & Medin, 1981). Many researchers now seem to agree that concepts may consist of any of these or combinations of them (e.g. Waldron & Ashby, 2001; Murphy, 2002). Most concept teaching procedures used in education presuppose the defining features view, which applies well enough to most school-taught concepts. These indeed usually are well defined (Howard, 1987).

Concepts and education: A conceptual approach to instruction

Knowledge largely is organised around concepts and new knowledge typically is acquired by relating it to existing concepts or by learning new concepts. Existing concepts filter input such as instruction and may block out any perceived anomalous input (Howard, 1987). Holding and being able to use a set of relevant concepts allows an individual to make much better sense of instruction and of the world. It follows, therefore, that education largely should be organised around concepts, a suggestion made by various authors (Howard, 1987; Hirsch, 1987). Hirsch listed well over a thousand concepts that he argued should form the basis of the American high school curriculum. Some examples of such concepts are quark, Typhoid Mary, roman a clef, and satire. Hirsch argued that a person who knew all of the listed concepts and could use them

adeptly would be "culturally literate", able to understand and deal effectively with other persons in American culture.

Using a conceptual approach to instruction involves analysing a subject matter into concepts and arranging instruction around them. It may involve first determining what concepts that the student already holds concerning the area, and either explicitly teaching him or her more adequate ones or organising instruction around the existing ones. It may involve teaching additional key concepts using various concept-teaching models (Howard, 1987; Tennyson & Park, 1980). Students can use these new concepts to make better sense of the world. For example, teaching meteorological concepts such as temperature inversion, rain shadow, and convection can help students better understand their local climate. Teaching such concepts as rule of law, republic, and consent of the governed can help students better understand their nation's politics.

Analysing a curriculum into concepts can be very illuminating for the instructor. It may show that some curricula are much simpler than believed and can be taught earlier and that other curricula are more complex than believed and should be introduced later (Skemp, 1979). For example, consider teaching high school students about the French Revolution. To fully understand the event, a great deal of background knowledge is needed which most high school students may not have, such as the concepts of monarchy, the divine right of kings, social structure of an agricultural society, consent of the governed and so

on. To fully understand the event, students may need to be taught these concepts first.

In science education, the need to adapt instruction to a wide range of possible student concepts and "misconceptions" now is widely recognised (Howard, 1987). An illustration is from Nussbaum's (1979) study of concepts of the Earth as a cosmic body held by children of different ages, replicated later by Vosniadou & Brewer (1992). The children studied had a variety of concepts, which developed with age, and to which instruction might have to be tailored. An initial concept was that the Earth was an infinite plain. Later ones were a flat disc, the round Earth being an object in the sky to which astronauts travel and the flat Earth being a cross section of the planet. Science instruction needed to be adapted to such concepts. Teaching students about why the Earth has seasons, for example, would be little use unless students were first taught the appropriate concept of the Earth, which they then could use to make sense of the instruction.

Concepts held by persons with an intellectual disability

One general view is that persons with an intellectual disability tend to have more impoverished concepts. They hold less information than usual and the represented category may have narrower boundaries. For example, the concept of fruit might be based on just a few concrete features and might not include less typical instances such as the date. One also might expect

individuals with an intellectual disability to know fewer concepts and to be less adept at using them to behave adaptively. Some concepts may be difficult or impossible for individuals with an intellectual disability to acquire because the concepts are too abstract or require certain specific abilities. For example, visual imagery deficits (Courbois, 1996) may make it hard to learn some visually based concepts.

Some researchers have examined various concepts held by individuals with an intellectual disability, but not a great deal of research has been done in this area. Some early research used a Piagetian framework, which does not feature much in current cognitive psychology approaches to concepts (Murphy, 2002). Piaget's proposed levels of cognitive development were used as a guide or various Piagetian tasks were used. For example, Woodward (1961) used Piagetian tasks to gauge number concepts held by 50 persons with an intellectual disability, who had an average age of 19 years. She found that their number concepts tended to be like those of normal children of between four and seven years old, who still were in Piaget's "concrete operations" stage.

Silverstein, Auger & Krudis (1964) examined the understanding of indefinite number concepts such as "few", "some" and "a lot" with 45 children with a mild or moderate intellectual disability. The children could differentiate the three concepts. Many of the children could write and recognise numerals, count coins, and perform simple addition and subtraction.

McEvoy (1989) looked at the concept of death held by several persons with an intellectual disability. The participants understood the finality of death but their knowledge of the ageing process and the life cycle was poor.

Lifshitz (2000; 2002) looked at the concepts of age and ageing, also using a Piagetian framework, with participants ranging in age from adolescence to old age. Their concepts tended to be impoverished and based on physical characteristics of people, such as wrinkles and needing a cane to walk. They were influenced by stereotypes. The emotional content of their concepts also was examined. Old age was perceived by many as frightening, especially among the younger participants (20-39 years old), but with participants' own increasing age, this fright lessened. Older participants tended to show greater acceptance.

A series of studies by Carolyn Mervis and her colleagues (e.g. Hupp & Mervis, 1982; Mervis, 1990; Mervis & Bertrand, 1995; Romski, Sevcik, Robinson, Mervis & Bertrand, 1995) has examined aspects of acquisition of terms and categories and conceptual development in persons with an intellectual disability. For instance, Hupp and Mervis (1982) investigated the acquisition of basic object categories by six children with a severe intellectual disability aged between eight and 18 years. Several studies investigated the acquisition of the "Novel Name—Nameless Category" (N3C) principle. The N3C principle is defined as the ability to rapidly attach a new word label to a basic-level

category. When normal children who know the principle hear a novel word in the presence of an unknown object, they may immediately attach the novel name to the new entity. When children have acquired this principle, there is a vocabulary growth spurt (Gopnick & Meltzoff, 1987).

Romski et al (1995) successfully taught 13 participants with a moderate or severe intellectual disability, who could not express themselves orally, to rapidly map the meanings of novel symbols. Mervis and Bertrand (1995) trained 22 children with Down syndrome, aged between two and three years old. Once they had learned the N3C principle, they could learn and generalise the meanings of new words even without explicit input.

Finally, one might ask about the self-concepts of persons with an intellectual disability. The term "self-concept" refers to a person's view of his or own self-hood or individuality. It might include perceptions about physical attributes, interpersonal skills, and academic and other abilities. A poor self-concept may lead to worse academic performance. Much research has been done on self-concepts of persons with learning disabilities (e.g. Elbaum, 2002; Dyson, 2003). Relatively little work has been done on the self-concepts of persons with an intellectual disability (e.g. Plesa-Skwerer, Sullivan, Joffre & Tager-Flusber, 2004, P. 120) and in how they view their disability. What concepts of themselves and of their intellectual disability do they hold?

The dependency syndrome described by Zigler (1973) mentioned earlier would suggest that many may have a poor self-concept, at least of themselves as learners. Plesa-Skwerer et al (2004) assessed self-concept in persons with two syndromes (Williams and Prader-Willi syndromes). The latter syndrome includes an insatiable appetite with the risk of severe obesity, and sufferers commonly saw their syndrome as quite a burden. Self-concepts of the participants also developed with age. Beart, Hardy and Buchan (2005) reviewed evidence on one aspect of the self-concept of persons with an intellectual disability; how they view the social identify of having an intellectual disability. They argue that having an intellectual disability is a powerful and stigmatising identity but that many affected individuals appeared unaware of this identity, which of course may not be such a bad thing.

Chapter Seven

AIMS OF THE PRESENT STUDY

A number of literatures have been covered selectively and now it is time to draw them together and set out the aims of the present study. A conceptual approach proposes that education works best when it proceeds from an individual's existing concepts. Instruction should be related to an individual's existing concepts and/or should involve teaching new concepts that an individual can use to improve functioning in a given domain.

This conceptual approach has not been applied very much to the education of persons with an intellectual disability. To the author's knowledge, the approach has not been applied in the key domains of work, leisure and retirement. Holding sound concepts of these should allow persons to behave more adaptively in the relevant domains and make informed choices among the plethora of choices as their lives progress.

What concepts of work, leisure and retirement do persons with an intellectual disability actually hold and therefore what sense do they make of instruction and other experience in these areas? Do they need to be taught more useful concepts? The concepts of work, leisure and retirement are quite complex. For example, work has such aspects as attitudes toward work, knowledge of an occupation's status, the countless tacit rules involved in finding and holding a job, the satisfactions and penalties that work entails, the

differences between paid and volunteer work, and so on. Leisure has many facets, such as attitudes toward it, its importance as a restorer of well-being, the many possible leisure activities, and so on. Retirement is also a very complex concept with many aspects, such as financial planning, living arrangements, and so on.

So, what do the intellectually disabled actually know about these domains and how do they view them? Little is actually known about their concepts. For example, Edwards (1995) queried whether persons with an intellectual disability understand and hold a work ethic, though some research has suggested that they enjoy work and have much work satisfaction. One might ask how they view such aspects as work satisfaction and stress on the job. Do many persons with an intellectual disability who hold jobs want to downshift or become sea changers, for example? Are they happy with their leisure lives? How do they view retirement? Some studies mentioned earlier suggest some may view retirement with some trepidation, but a more extensive study may shed more light on this question.

Determining the existing concepts of persons with an intellectual disability of work, leisure and retirement is of intrinsic interest and will give a much better focus for instruction. Knowledge gaps can be identified and education efforts much better targeted and evaluated.

The present study had two major aims. The first was to determine the concepts of work, leisure and retirement held by a sample of 60 persons with an intellectual disability who lived in Sydney. In addition, a variety of data were gathered about their current and former work and leisure activities. Most research on the latter topic is from the United States, and it is interesting to compare their findings with those of an Australian sample. The second aim was to develop and test a conceptually based education program derived from the findings of the first part of the study. The program would aim to fill the knowledge gaps revealed and to teach useful concepts that could be used to behave more adaptively in these domains, as well as make informed choices that affect their lives in these domains.

Chapter Eight:

STUDY 1- DETERMINING EXISTING CONCEPTS OF WORK, LEISURE AND RETIREMENT

The aim of Study 1 was to determine the existing concepts of work, leisure and retirement in a sample of 60 adult persons with an intellectual disability. The main research techniques used were a simple classification task involving pictures of work and leisure activities and a structured interview.

Researchers have used several major methods to determine what concepts a particular individual holds; e.g. what information those concepts contain (Howard, 1987). Two major ones, which were used in the present thesis, are as follows. The first is an extensive interview to probe an individual's knowledge, used in a variety of studies mentioned earlier (e.g. Nussbaum, 1979; Vosniadou & Brewer, 1992; MacEvoy, 1989). For example, to determine children's concepts of the Earth as a cosmic body, Nussbaum (1979) asked children of different ages a series of questions to determine how they conceptualise the planet and how these concepts change with age. This interview procedure allows an individual's knowledge to be probed in depth but can be quite time consuming. Many studies of individual's concepts with this method tend to have small samples as a result.

A second way, used more often to study simpler artificial concepts (e.g. Howard, 1987) is a classification task to determine what an individual knows,

which also may test how adeptly an individual can use a concept. For example, to determine whether an individual has a concept of square, a variety of squares and non-squares can be presented, with the individual being asked to say which is a square and which is not. If the individual can do this more or less accurately, he or she is judged to have a sound concept of square. The classification data also can be used to determine what precise knowledge of squares that the individual has, and if there are any gaps. For instance, if an individual consistently classifies oblongs as squares, his or her concept evidently does not include the feature "has four sides of equal length". Much of the cognitive psychology literature on concepts relies on classification tasks to determine what knowledge an individual holds (Murphy, 2002).

A variant of this method involves asking the participant to provide instances and to say why they are instances. For example, one might ask an individual to draw some squares and say why they are squares, again seeing if the instances are indeed examples. This classification procedure has the merit of being able to determine if an individual actually can use a concept, but it is not practical to arrange classification tasks for many complex concepts. Too much time would be involved.

Study 1 of the present thesis used both methods, though it relied largely on the interview because it was very difficult to arrange classification tasks for all the knowledge examined. A simple classification task was used to determine

if participants could accurately classify activities as examples of work or leisure and as a check on interview data. Participants also were asked to provide instances of each to test further their concepts. An individual interview also was used to probe their knowledge in depth.

However, interviewing persons with an intellectual disability can have problems and a number of considerations should be heeded by the interviewer. There is a substantial literature on the problems involved. For example, Dattilo, Hoge, and Malley (1996) list several special considerations to ensure more accurate information from interviewees, which were heeded in the present study. First, it is best to interview both the person with an intellectual disability and the latter's main caregiver together. Second, the interviewer should first establish a positive rapport with a short and casual chat before beginning the interview. The interviewer should have all the materials ready before the interview starts, should use pictorial representations of spoken words, and use open-ended questions for clarity. Another problem is how to interpret non-responses to questions. An interviewee may not answer a question because he or she does not wish to answer, does not understand part of the question, or perhaps all of it. The interviewer can probe further in cases of non-response, but still it may just not be possible to interpret it correctly.

METHOD

<u>Participants</u>

Obtaining a sizeable sample of persons with an intellectual disability is difficult in itself and the University of New South Wales Ethics Committee placed severe restrictions on recruitment of participants. No potential participant could be approached directly, for example, and permission to participate needed to be secured from a carer if the individual had a guardian. However, it was possible to recruit a reasonably large sample of 60 participants from two main sources. Fourteen participants (who had Down Syndrome) were recruited through an advertisement in the newsletter of the local Down Syndrome Association. The rest were recruited through the Sunnyfield Association, an organisation which provides sheltered workshop employment as well as accommodation. Many participants worked at the Sunnyfield sheltered workshop. Criteria for employment at Sunnyfield include an IQ score of 70 or below and significant support needs, as determined by Centrelink, the Australian governmental human resources organisation. There were 35 females and 25 males and all lived in the greater Sydney area. Their median age was 36 years old, with a range from 19 to 71. All but seven were born in Australia. Their educational levels were as follows. Most had attended a special school or special education unit at a public school. Twenty-two had attended school up until to the ages of 12 through 17, another 22 until age 18, eight until age 19-22, and eight could not recall. Many were living in the community.

All participants had been diagnosed as having an IQ score below 70 either by Centerlink or by the school system. However, specific IQ scores were not available so it was not possible to determine degree of intellectual impairment or analyse data according to degree of impairment.

The sample is not random but is fairly varied. A random sample is not crucial for a study such as this.

Apparatus

A three-section questionnaire was developed about work, leisure, and retirement concepts to tap knowledge in each domain and to gauge each individual's work and leisure activities and histories. The questionnaire is presented in Appendix 1. Within the first section, twenty-one pictures depicting persons engaged in various work (11 pictures) and leisure (10 pictures) activities were used for an initial sorting task into either work or leisure. Topics included knowledge of what made an activity an example of a work activity, the work ethic, occupational status, volunteer work, and money management, as well as the types of work participants had done and whether they would prefer other types. Questions in the leisure section asked participants to identify leisure activities and what made them leisure activities. The participants were also asked what leisure activities they currently participated in and any additional ones they would like to participate in. The retirement section

contained questions on their attitudes towards retirement and how they pictured their life when retired.

<u>Procedure</u>

Consent of each participant (and carer if needed, as when the individual had a designated guardian) to take part in the study was obtained first. Each participant then was interviewed individually or with a carer, in one session, at either a work site or at home. The author interviewed all 60 participants. Seven were interviewed with a carer, and the rest were interviewed alone. The interview took approximately one hour and the participant could stop it at any time.

The interviewer began the interview informally and then asked for demographic information: details of age, education, and place of birth. Then the participant was shown two signs, one labelled **Work** and the other labelled **Play**, and was given the 21 pictures and asked to put each into its appropriate category (e.g. a work or a leisure activity). Ability to accurately categorise examples is a good index of holding adequate concepts of work and leisure. Then the interviewer asked the set questions from the questionnaire in a fixed order. At the end, the participant was asked if he or she would like to learn more about any subject raised.

RESULTS

Responses differed little between interviewees interviewed alone or with a carer. The carer's most common contribution was to prompt the interviewee's memory when he or she could not respond. For example, if initially unable to name a retiree, the carer might name one (e.g. "What about Uncle Bob?") and then the interviewee would fill in details.

<u>Work</u>

Most participants were found to have a solid knowledge of the concepts of work and leisure, but with some gaps. Most participants readily sorted the 21 pictures into the appropriate categories, with the mean number of errors being 3.67, ranging from one to six errors. When asked to give further examples of two work activities, 45 were able to do so. The most common answer (24 participants) was "refurbishing stereo headphones" (a main work activity for Sunnyfield, where many worked), followed by packing (11), kitchen hand work (11) and office work (7). The top four choices for work activities were all jobs at Sunnyfield, and in many instances, the participant listed jobs that he or she either did or had done. Most also could state what made these activities instances of work. The most popular response was that they were all activities that they would do at the workplace (19). The second was that these were jobs (10), and two said because they involved a boss. Eleven could not answer the question. When asked to name activities portrayed in the 21 pictures (work or

leisure) that a person was paid for performing, 57 cited the work activities, one answered the leisure ones and two could not respond. Most could name specific jobs that paid wages. The most common responses were packing headphones (16 participants), packing (17), office work (18), kitchen hand/server (16), sales clerk (13), bus driver (17), doctor/nurse (12), and cook (10).

Understanding of volunteer work was much more limited. Participants were given a definition of volunteer work and asked if they knew anyone who had done such work and to say more about that individual. Most gave only very vague responses here. Only 27 reported having done volunteer work while 32 said that they had never done it, and one could not answer. Of those who had done volunteer work, six said delivering food to the elderly, two named helping out at a local charity, three said committee work, three said organising sports programs for the disabled, and two cited fund raising for Sunnyfield Homes.

Most participants (55) apparently had little or no notion of job prestige. Whether they actually hold this knowledge is quite hard to gauge but was attempted by offering six occupation names (doctor, cleaner, gardener, secretary, plumber, teacher) and asking which ones the participant (and then a friend or relative) would be "proudest" and "least proud" to have. Only two were judged to have some notion of status by citing more prestigious jobs, while three showed a partial understanding. Most chose jobs that they were most familiar with or actual occupations that they, a friend or relative held.

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Most had some notion that some jobs required more study than others to perform and could give examples of such jobs. Fifty-one answered that some jobs did require more study, while five answered that none did and four did not know. The jobs they listed that required much more study included: doctor (24), office worker (8), teacher (6), computer related jobs (3), lawyer (3), writer (2) and trades person (4). Related to this question was whether participants would like to perform a different job than their current one. Twenty-nine replied "yes", 25 said "no", five had no answer and one said "sometimes". Of the new jobs desired, five cited office work, three packaging, three working in a store, two kindergarten teaching, two electrical work, three gardening, one kitchen hand work and one headphones work. When asked if more training was required for these new pursuits, 21 replied "yes", six said "no", and the rest had no reply. Types of additional training needed that were cited included TAFE courses (3) and on- the- job training (7).

Table 1

Percentage of participants specifically citing a leisure activity as ones in which they participated in during high school, at the present time and that they planned to take part in during retirement. Many cited more than one activity in each category.

<u>Table 1</u>

Activity	In High School	Presently	When Retired
Swimming	40	37	13
Walking	0	27	12
Cricket	18	15	0
Bowling	8	27	7
Other sports	100	0	17
Watching TV/Videos	8	72	25
Going to movies	10	48	0
Listening to music	0	28	15
Dancing	5	22	0
Out with friends	10	12	13
Clubs	0	15	10
Out to eat	0	20	0
Shopping	3	20	7
BBQs	0	7	0
Travel	0	10	17
Church	0	5	0
Crafts	0	5	0
Reading	0	7	7
Computer games	0	12	3
Volunteering	0	0	12
Other	0	0	5

Participants were asked about four specific reasons and benefits as to why a person worked. Most could state multiple reasons for working. Fifty-six said work satisfaction was a reason why people worked, 57 that money was, 58 that social contacts were, and 59 "to feel competent" (to do a good job). However, participants showed relatively poor money management knowledge and skills. When asked where they would get money if they did not work, 11 did not know, 23 specified the bank, 12 a pension, four parents, two savings in the bank, three from staff members of Sunnyfield, one from an inheritance, two from unemployment benefits, and one from nowhere. When further questions were asked on banking, only seven demonstrated much understanding of the banking system, while 18 demonstrated a partial understanding (that their pay from work went into the bank), and 35 showed no apparent understanding.

Work attitudes on the whole were very positive. Most stated a liking for work, were judged to have a strong work ethic and understood the necessity for people in a society to work. Forty-two could not state anything bad about having a job. Of the 18 that could, the following negatives were listed; problems getting along with co-workers (17), not enough pay (1), trouble concentrating on work (1), did not like doing a particular job (4), got bored (2), got hurt (2), and one commented cryptically "only if safe". This may be related to a recent accident at Sunnyfield in which two people on the

job were injured. When asked what was good about having a job, only four did not know. The rest gave multiple reasons which included: getting paid (28), friends (29), satisfaction (6), they enjoy/like their job (25), like their supervisors (8), enjoy learning new things (3), to please the customer (2), and completing work (3).

Several questions gauged aspects of the work ethic. When asked if everyone should have a job, 53 replied "yes", three "no" and four did not know. When asked if it was good or bad to call in sick to work when healthy and then go to the beach, participants overwhelmingly felt that it was bad. Fifty-five felt this was bad to do once a week and 56 felt it was bad to do even once a month. When asked about a person who could work but refused to do so, 47 replied that it was bad. Specific reasons it was bad were because the person was lazy (6 responses), you would get fired (6), one would not be taking the opportunity to work (1), you should not get the dole (1), and you would get no pay (1). When queried how they would feel if they did not have a job, only one replied that he would be happy. Most responses were negative, including feeling bad (7), bored (5), sad (14), upset (6), depressed (4), would miss work (2), not have enough money (1), feel lonely/ guilty/ terrible (3), and that there would not be enough headphones for the plane passengers (1). Finally when asked what would happen if everyone in a society stopped working, most responses were negative (53),

while one was ambivalent and six did not know. Examples of responses were "could not live", "chaos", and A"could not go to doctor".

Staff at Sunnyfield was not interviewed explicitly. However, some anecdotally did confirm the strong work ethic and enjoyment of work of participants. The participants rarely take sick leave and come to work even when ill, and may have to be sent home.

Some questions asked about their personal work histories. All but two were in or had been in the work force. All but four currently were working; 37 full time, and 19 part time, and four retired. The two most common first jobs each had held were packaging (10) and refurbishing headphones (10). This work mainly was done in a sheltered workshop, where another six did unspecified work. Five were kitchen hands, three worked in a supermarket, three did office work, and four worked in trades. Their current jobs also show the highest number refurbishing headsets for airlines (20) and packaging (21). Seven currently did office work, three stocked shelves, three were kitchen helpers and one made light fittings.

Leisure

Most participants had a solid concept of leisure and its importance in human welfare. Most participants could readily categorise the leisure activities depicted in the pictures. Almost all could name two further leisure activities. All but three mentioned sports activities (bowling and swimming

being the most common), ten mentioned watching television and videos, six going to movies, six dancing, five craft work, five shopping, five listening to or playing music and two mentioned travel.

Most understood the value of leisure as a restorer from work stresses. When asked what it would be like if the participant had to work all the time, 45 said it would be bad, five said it would be good, two were indifferent and four did not know. For those who said it would be bad, 13 said they would be tired, eight said it would be bad/terrible, five said it would be stressful, three boring, five sad, one that their friends would not like it, one that he would go crazy, and one said that he likes his time off.

Leisure was important to them and most reported satisfactory and varied leisure lives, with median reported time spent on leisure being 20 hours per week, with a range of seven to 36 hours. Participants reported taking part in a wide range of leisure activities. Table 1 presents the main current activities cited, sports of various kinds being the most popular. When asked if their leisure activities involved others, 58 answered yes, while one said just her and one had no answer. When questioned who the others were, 50 answered family, 49 friends, two a partner/husband, four staff, and one her pet cat. When asked who chose their leisure activities, most participants (55) answered "themselves", three said "others", and two did not know.

When queried what additional leisure activities they would like to participate in, only 24 gave additional ones.   These additional activities included playing tennis, additional travel, and horseback riding.   When asked if there was anything stopping them from taking part in additional leisure, they cited lack of transport (4), money (3), cannot do alone (3), lack of time (4), a physical impairment (2), no equipment (2), lack of training (2), no ability (1), no information (1), and have not organised it yet (2).

Participants were asked how their leisure activities had changed since high school. Table 1 shows that the typical pattern was a lot of sports in high school with relatively little television viewing but then a shift to more social activities, such as doing things with friends, watching television and movies, and going to clubs.

Retirement

Four participants already had retired. Of the others, most had only a relatively poor concept of retirement at best and of the need to prepare for it. Eight had little or no knowledge, which made some follow-up questions about retirement moot. Most could name someone who had retired but were confused about typical ages at which people retire. Twenty-three did not know and 26 said "in the 50s and 60s".   As to why people retire, many reasons were given; "got old, ageing" (16), "the person wanted to" (8), "due to law" (5), "got sick or hurt" (9), "because they could not cope" (1), and

"because they were tired/exhausted" (6). Ten gave very idiosyncratic reasons; "to get married", "young people are more computer competent", "to travel", "lose job", and "people change". The rest did not know. Most could list some leisure activities of the people they knew who were retired. For instance, nine cited gardening and housework, ten travel, and seven shopping.

Some questions were asked about their own possible retirement. Many did not seem to understand that they would eventually retire and how that would be funded. Only 34 said that there will come a time when they stop working and retire, 15 said "no", one said "it was a possibility", and six could not answer. When asked in how many years they thought they would retire, 34 did not know.

Many had relatively little understanding of how they would fund their retirement, or the necessity to fund it. Participants were asked if they needed to save money over their working life for retirement and 46 responded "yes", seven "no", and seven did not answer. They were asked if the bank will keep giving them all the money they wanted even if they had not saved it and many answered yes. Only a few realised that money in a bank account could run out eventually. When asked how they would pay their bills when retired, 25 could not answer at all. Eleven said "the bank", nine said "a pension", four said "parents", two said "inheritance", three said "savings",

three said "Sunnyfield Staff", two said "a job", two said "investments", one said "petty cash", and one said that he would tear up the bills! Clearly, financial aspects of retirement are not well understood.

Many had only a vague idea of what leisure activities they would do when retired. When asked about leisure activities they thought they would participate in, some cited somewhat different activities from their current ones (see Table 1). Some unusual ones were (with one participant citing each): buying a car, buying a farm and getting married. Of the four participants already retired, travel was a favoured leisure activity. One had just been to Melbourne, and talk of his trip permeated his entire interview. Their other retirement activities were more sedentary, including television/movie viewing, reading, retirement clubs, bush walking, and shopping.

Attitudes toward retirement were mixed. When asked how they pictured their life when they retired, only half did so positively, 20 had a negative response, one seemed ambivalent and the rest had no answer. Of the positive group, 20 felt it as "good/happy", while ten felt it was just "OK". Some of the negative responses included "being sad", "having little money", "would be unemployed", "would be bored", "would miss friends from work", and "would need more money".   These responses all

correspond to the reasons and benefits they reported for working, that is, job satisfaction, money, social contact and feeling competent.

When asked if they specifically wanted further information about retirement, 43 said they did, to help prepare them for retirement. But 14 said no and three had no answer. Finally, when asked if they would like to learn anything more about the topics in the questionnaire, 23 said no, and 19 cited more about retirement.

DISCUSSION

The main findings may be summarised as follows. Most participants had a basic knowledge of work and leisure and had a strong work ethic. They understood the need for a balance between work and leisure, and that the latter is a restorer of mental well-being. Most were quite happy with their current work and leisure activities and did not particularly want to know more about these things. However, the study revealed some gaps in their knowledge. Most had little understanding of volunteer work and occupational status. Knowledge of and the need to prepare for retirement were far more limited, and many indicated that they wished to learn more about these topics. Knowledge about ageing and the human life cycle were poor. Knowledge of money and banking in general were also generally poor, though only two stated that they wished to learn more about these topics. These results give an intriguing and novel insight into how persons with an intellectual disability view these important domains.

The data also suggest some key targets for an education program to improve their functioning in these three domains. There seems to be relatively little need to educate further about most work and leisure matters with these participants, but quite a lot of need to educate them further about some aspects of work, such as voluntary work, and about retirement. Knowledge of money and banking in general are needed. There did not seem

to be any pressing need to educate about occupation's status, however. Such

knowledge might only make the participants dissatisfied with their present

jobs.

CHAPTER Nine:

STUDY 2- CURRICULUM DEVELOPMENT AND
EVALUATION

The data from Study 1 showed some key deficit areas, particularly about aspects of the life cycle, banking, budgeting, volunteer work (which could be an alternative to paid work for work satisfaction before or after retirement) and particularly about retirement. Study 2 involved devising and delivering an educational program based on the findings of Study 1. The education program aimed to improve participants' knowledge in these deficit areas. An eight-week class was run to gauge the effectiveness of this education program with a sample of participants from Study 1.

The curriculum used for the eight-week class was developed using a conceptual approach. Instruction partly focused on teaching component concepts needed to understand the broader concepts. For example, to understand the concept of retirement and to adequately plan for it, an individual needs to know the concepts of the human life cycle and the ageing process; how people change with age. These concepts were explicitly taught. The knowledge and skills taught are presented in Appendix 2 (a booklet each class member was given to complete and retain for themselves) and are described in more detail below.

The curriculum was delivered with a variety of teaching methods, which also are described in more detail below. Some methods were conventional ones used for non-disabled students and some were methods tailored for individuals with an intellectual disability. The level of instruction was kept as concrete as possible, the instructor relating material to the participants' personal experiences as much as possible. For instance, each class involved reviewing various activities that each participant had done as a child and as an adult.

The program delivered to the participants covered the following major topics, organised loosely into work units (also see Appendix 2).

Volunteer work

This part involved defining and elaborating on the different types of work that exist (paid jobs, home chores, volunteer work) and getting across the notion of volunteer work as something that the participants themselves could do. The unit began by asking what interests each participant member had and then relating these interests to possible examples of volunteer work. Then it was noted that there were several types of volunteer work that they would be interested in and would enjoy performing. The unit described how volunteer work could provide an enjoyable, satisfying activity for them currently and when they eventually retired, giving them ongoing friendships

and the chance to exercise a variety of skills.   The unit also outlined ways in which to find out about the availability and location of volunteer work.

The concept of the life cycle and the ageing process

The aim of this part was to teach the concept of the human life cycle and the ageing process, essential to understanding and planning for a person's own eventual retirement. Participants already had some notion of their own past lives. They were aware of what had already transpired in their own lives, but had difficulty understanding and projecting their futures. As the concept of their individual future expanded, they could make decisions that would directly affect their future daily lives, such as accommodation, activities, and money management.   The abstract concept of time was difficult for them. For instance, few participants knew their birth date and most did not know their current age.

The unit began by reviewing details of their individual past lives, using both words and pictures. For instance, such pictures might be photographs of the participants as children, which each participant brought in to the class. The instructor pointed out how each individual had changed in appearance from that depicted in their photographs as children. The physical characteristics at different ages were pointed out. For example, they were shorter as children but taller by adulthood and growth then stops.

With age, various physical characteristics change, such as hair colour (it goes grey), skin smoothness (wrinkles appear), and amount of hair (signs of balding appear in some persons). Because of the range in ages in the class (from 20 to 58 years old), a wide range of physical characteristics was available for the class members to observe. In class, the physical characteristics of various ages were noted and discussed, as well as those of friends and workmates. Each participant could develop the concrete concept that he or she had been a baby, a child, and then an adult, with greatly differing physical characteristics at each stage.

Another aspect of the life cycle and the ageing process is that an individual's interests, leisure activities, and working life may alter over time. The instructor asked about and then discussed the individuals' own activities, interests, work, and leisure pursuits during both childhood and adulthood. They could draw on knowledge of what they had done as children (schooling, sports, etc.) and what they currently do as adults. They learned to compare their activities during childhood and adulthood and could see how and why their activities had changed. Interests may change due to less energy and stamina with age, for example.

Banking and money concepts and skills

Chapter 1 reviewed some studies on teaching various money- handling skills to persons with an intellectual disability. Study 1 revealed that participants

had a number of deficits in this domain. Each participant typically had little or no concept of a bank account, that he or she had an individual bank account and that money had to go into it for money to be available to be taken out. For instance, many stated that the bank would keep giving them money indefinitely and that all that anyone needs to do to get money is to go to an ATM, put the card and PIN number in, and money will come out. Some participants had some notion that their pay from the sheltered workshop went to the bank, but were not aware of the details, the amounts involved, or how to access that specific money. They did not understand how the bank differentiated their money from that of other persons, or that the bank would only provide money that was actually in their own account.

The basic concept of a bank account and the skills of depositing and withdrawing money were taught. Actual bank deposit and withdrawal slips were used, along with play money to represent their actual pay from work. The participants were taught that a deposit puts money into their account (for instance, from pay), and that a withdrawal takes money out of their account. The participants were asked to role-play giving their pay to a banker, who then placed the sum into their account. Also taught was how the bank could identify and service their particular account, noting how the bank could tell where to put their money by using both their name and their bank account number. Filling out the appropriate slip taught them what was

needed to specify their individual account, and how to determine the correct amount of a transaction. There was daily review and drill on use of the deposit and withdrawal slips.

Participants also were taught the concept of an ATM card and the skill of using one. The notion of an ATM card was introduced as a way to withdraw money from an account. Most participants had seen an ATM card used by others, but only one had ever actually used one. Most relied on family members or staff at their residence to use an ATM card or to provide cash when they needed it.

Participants also were taught the notion of and the use of a credit card. Only one participant actually had a credit card. All participants had seen credit cards used in shops but only one really understood the difference between a credit card and an ATM card. This difference was covered briefly in the class as follows. Actual ATM and credit cards were shown and were contrasted, and it was pointed out that the ATM card was linked to a specific bank account while the credit card was not. In order to use the ATM card, they had to have enough money in their bank account, money that came from their pay or pension. This was not the case with a credit card. Safety issues concerning the use of an ATM card, such as not revealing a PIN number to anyone, also were discussed.

Some basic money management skills were taught. In particular, the notions and skills of saving money, of making a budget and of paying bills, were taught on a very basic level. The activities covered by the term "budgeting" cover a wide span, from planning to meet a short- term goal to planning to meet a long -term goal such as funding one's retirement. No participant had ever made an actual budget. Few even paid any bills, with their family or staff members doing so. Those living in group homes typically received money only for special occasions, such as going to the local Returned Services League (RSL) club.   Any bills were taken care of by staff at their group home. For those living with their families, a family member might give them cash for a specific activity, and also paid the bills.

Two books were used to develop material for this component. The first was "The Everything Budgeting Book" (Drenth, 2003), which was used for definitions of basic budgeting terms. The second book was "The Sink or Swim Money Program" (Whitcomb, 2002). This book outlines a step-by-step program that begins with young children receiving an allowance and then learning how to spend that allowance wisely. The program ends with the situation of a young person being fully responsible and able to handle all of his or her finances. Due to the step-by-step nature of the book, the material is suitable for persons with an intellectual disability. A major budgetary concept taught to participants in the present

study was that of budgeting for a small, rapidly achieved goal, an early step covered in the book.

Instruction on budgeting began with participants being asked if there was anything that they wanted to buy which they could not pay for with the money from one pay packet. Two things they cited were a portable CD player and a one-week holiday staying with relatives on the Gold Coast. The class then priced each purchase at $100, partly from commercial printed material provided by the instructor. The class then discussed saving money and how to get the $100 sum needed. Using the play money, the participants were taught that the needed sum could be saved in five pay periods by retaining $20 per pay period.

The concept of retirement

This was the final topic taught in the class. The material followed from the material on ageing and the life cycle and notions of how a person's interests and activities may change with age. Basic concepts from the previous components were used as building blocks; volunteer work providing an enjoyable activity, physical changes in the life cycle, the basic concept of banking (that a bank account is funded by pay and pensions), and of budgeting (how to save and pay for things).

Participants were taught that each of them would undergo further physical changes with age, just as they had undergone physical changes

from childhood. Three participants in the training group were nearing retirement age and all participants could see how these three older persons looked and how each of them eventually would look. The concept of retirement was then taught in some detail.

METHOD

<u>Participants</u>

These were twenty individuals who had participated in Study 1 and who worked in the sheltered workshop at the Allambie site of Sunnyfield where the training study was conducted. They were selected from all those at this site who volunteered for the study. Some criteria for selection for participation in Study 2 were that the individual had to be able to express him or herself verbally according to the author's judgment, and could work independently or with minimal supervision. They are not a random sample of the 60 participants in Study 1 but no comparison was to be made between this selection and the 60 participants. The comparison was between two randomly selected groups from this 20.

Participants were randomly assigned to either a control group or the training group, each with ten members, by drawing names from a hat. . The training group was limited to ten participants because the physical space available as a classroom could not fit more and because many participants needed much individual instruction in certain areas. The training group had

an age range from 20 to 58 years old, with an average age of 38 years old. Five participants were female and five were male. However, one participant in the training group injured her foot very early in the course and could not complete the class. Her data were excluded from analysis. The control group had three males and seven females, with an age range from 22 to 64 years old, and an average age of 36 years old.

<u>Apparatus</u>

Sunnyfield Homes made its canteen available for class sessions. Training sessions were conducted by the author from 9am to 10am three days a week during the working week. The canteen was located next to the sheltered workshop where the participants worked. A few canteen workers usually were at the other end of the canteen preparing tea and lunch, but the space was quiet. Participants sat around a large table. Each participant was given a workbook to complete during the class. Pictures and notes went into their workbooks. These workbooks were brought to class every day by one of the class members, and returned to the office of the Sunnyfield manager at the end of each session.

<u>Procedure</u>

Before the first class session began, all twenty participants were given a pre-test to gauge their knowledge of the areas of the life cycle, banking, budgeting, volunteer work and retirement. The aim was to determine their knowledge of these topics and see if this knowledge increased after the class had finished, which would be assessed by a post-test. The author interviewed each participant individually in the canteen. The test questions are presented in Appendix 3.

The class was conducted between 9 and 10 am, three days a week (Tuesday, Wednesday and Friday) during normal working hours, for eight

weeks.   Each class member was excused from work at the sheltered workshop to attend sessions.

The curriculum and teaching methods used have been described above to some extent and in Appendix 2. A few more details are presented here. A variety of teaching methods were used; discussions, exposition by the author, role-plays, and so on. Each participant used his or her booklet to record and review class material during each session. Most participants needed help to write in their booklets, and the author and two adept class members helped them to do so.   When a session was over, the students handed in their workbooks that were returned to the manager's office.

Each training session proceeded as follows.   First, the class members assembled around the table with their individual workbooks in hand.   The material from the previous session was reviewed orally to refresh their memories.   Next, the new information to be learned that session was introduced and then was presented in several ways, often in as concrete and personally relevant way as possible. An example is in introducing the concept of a short-term financial goal (described earlier). First, participants were asked to name something that they wanted to buy in a few months, which they would have to save up for.   They cited a portable CD player and an upcoming vacation with family members.   They were asked how much of their own money they wanted to spend for the holiday.   Most said $100.

Then it was discussed that if they "saved" (did not withdraw) $20 from their account each payday, then in 10 weeks (five pay periods), they would have the desired amount. For the CD player, most had no idea how much one would sell for. Current ads from Target, Big W and K -Mart (local shops that they all frequented) were presented to price several CD players. After looking through these ads, the class members determined the item that they wanted and then the class reviewed how they could save for this purchase. Also discussed was the idea of more safely saving for short-term goals by depositing money in a bank account rather than keeping the money at home. To back up the idea of saving $20/week in the bank, play money was counted out and participants could learn that five $20 bills equalled $100, the sum needed for both purchases. The material covered during the class session that day then was reviewed. Finally, the class was invited to ask any questions that concerned them.

Three weeks after the class had concluded, all participants in the training and control groups were given a post-test (see Appendix 4) of their knowledge of volunteer work, the life-cycle, banking, budgeting and retirement. The same questions were asked as in the pre-test with a few exceptions mentioned below. However, no six-month or 12-month follow-up was possible. The pre-testing, post-testing and all training sessions were carried out by the author.

RESULTS

The training class ran for the most part successfully, without major difficulties. The class climate was relaxed and instruction proceeded well. Participants who spoke little at first opened up after a few sessions and then all participants contributed freely to each session. All class members seemed enthusiastic about attending the class. During a few sessions, some personality conflicts did arise. For instance, sometimes all participants wanted to contribute at the same time. However, these problems were resolved quickly and participants' turn taking improved over the eight weeks.

Tables 2 to 11 present the data for each group for pre-tests and post-tests. Overall, the data suggest that at least some participants in the training group acquired much useful knowledge during the course. However, some members of the control group apparently did too, though not as much as the training group. As noted later in the discussion section, this learning may have been due to interaction at work during the week with members of the training group.

Two major types of comparison can be made in the data. One type is comparison between pre–test and post-test results of each group and the second is between data of control and training groups. Data for analysis are numbers of participants in each group selecting an alternative or being able

to perform some task, such as counting. No inferential statistical analyses were performed on the data because the sample size is very small and statistical power would be very low, and also because many comparisons were made. This again limits the conclusions that can be drawn but is often a problem in studies with persons who have an intellectual disability. Such studies typically have small sample sizes.

Tables 2 and 3 present both the pre-test and post-test results of both groups on the questions related to volunteer work. Questions of particular interest are whether more participants in the training group were able to recognise whether or not they had done volunteer work in the past and were more likely to do volunteer work in the future. Table 2 shows that at least some class participants learned some material about volunteer work from the course. The number of class members stating that they had done volunteer work in the past rose from three to five out of the nine (although in the control group, this number rose from three to four) and the number of class members stating that they would do volunteer work in the future rose to nine. The latter total declined slightly in the control group.

The final two questions were asked only on the post-test. However, the data show clearly that all class members stated that they knew where to find out about volunteer work while only six in the control group did. Training group responses of where to find out about volunteer work included

the following; asking the staff at Sunnyfield, contacting Centrelink, asking a youth leader at church, asking parents, or phoning such organisations as Meals-on-Wheels. There was little difference on whether they would do volunteer work when retired, six in each group stating that they would do volunteer work when retired. Three training group members gave a definite "no" response to this question. In the control group, two said "no", one said "maybe" and one had no response.

Table 2

Number of participants in training and control groups responding "yes" to various questions about volunteer work. N/A means the question was not asked in that condition.

Question	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Have done volunteer work	3	5	3	4
Will do volunteer work in the future	7	9	6	5
Can state where to find out about volunteer work	N/A	9	N/A	6
Will do volunteer work when retired	N/A	6	N/A	6

Table 3 lists some responses to the question of what types of volunteer work participants might do in the future. During the class, the types of volunteer work had been discussed. The training group participants listed more types between pre-test and post-test; two more cited bush care/gardening and one cited Meal-on-Wheels. However, the control group participants also listed more responses.

Table 3

Number of participants in each group citing various types of volunteer work
that they would do.

| | Training Group (n=9) | | Control Group (n=10) | |
Type of work	Pre-test	Post-test	Pre-test	Post-test
Great duck race*	2	2	1	3
Help children	1	0	1	0
Bush care	1	3	0	1
Disabled/hospital	1	1	0	0
Meals-on-wheels	0	1	2	2
Church	1	1	0	0
Merry Makers	0	1	0	0
RSPCA	0	0	0	2
Wrap presents	0	0	0	1
Any kind	1	0	1	0
No work appeals to the individual	0	0	0	1

* An annual fund raising event held at Sunnyfield Homes.

Several questions aimed to gauge whether training group participants
had learned more about ageing and the life cycle. Some questions were
answered in ways that suggested participants had acquired knowledge about

these topics. All members of both training and control groups were able to distinguish between their childhood years and their adulthood years. They recognised that they had spent much of their time as a child in school and as an adult at work. All participants answered that they were the same person as both a child and adult, although one control group member added that he felt different as an adult. When asked in what ways they had changed from childhood to adulthood, all training group members gave plausible answers while only eight control group members did, and two did not know. Some stated a number of differences between themselves in childhood and in adulthood. These included "have got bigger" (13 participants), "was smaller as a child" (three participants), "have changed" (one participant), "now wear glasses" (two participants), "not as sick as when younger" (one participant), "have grown a beard" (one participant), and "dye my hair" (one participant).

Table 4 presents answers to the question of which of their activities had changed from their high school years to their adult years. Sports of various kinds were the most popular cited activity in high school. Current activities in adulthood included several organised sports such as the Special Olympics and bowling, but typically were such activities as watching television, listening to music, and social pursuits such as going out to clubs, movies, dancing venues and visiting friends. Table 4 shows that more training group participants could state ways in which their lives had

changed. For instance, three did not know in the pre-test but all knew in the post-test.

Participants also were asked to state why their activities had changed with age. All class members could state reasons, such as changing interests, lack of availability of formal sports teams, and physical problems that prohibit participation in sports they once had played. One stated "too old for sports because age changed you". Only six participants in the control group could state why their activities had changed.

To further gauge knowledge of ageing, participants were asked how they would look when they had retired. Again, training group members had learned more; eight gave appropriate answers such as "will have grey hair", "skin will wrinkle", and "will be wiser". Only one training group member did not give a response. Of the control group, six could give appropriate answers, while four could not. Participants also were asked to forecast what leisure activities that they would participate in when retired. These stated activities were very similar to their current adult activities. The most commonly cited activities were watching television, doing things with family, going for walks, playing tennis, talking to friends on the phone, swimming, eating out, travelling and fishing. One control group participant responded that she would stay forever young like Madonna.

Table 4

Number of participants citing activity changes of various types between high
school and adulthood

Activity change/s	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Activities have not changed	0	3	0	1
Interests changed	2	3	1	0
Not on sports team	0	1	1	1
Physical problem	1	1	0	0
Do more as age	0	1	1	0
Because no school	1	0	1	3
Too old	0	0	0	1
Taught to use bus	1	0	0	0
Watch sport now	0	0	1	0
Parents choose	1	0	0	0
Changed – accident	0	0	1	0
Do not know	3	0	4	4

Several questions aimed to assess what knowledge participants had acquired of banking and money handling in general. The pre-test had shown that few participants had a budget or paid their own bills. Only two training group members reported paying bills (for entertainment, clothes and food) and only two control group members reporting paying bills (for room and board). On how their bills did get paid, there were a variety of responses, as shown in Table 5.

Table 5

Number of participants in pre-test answering with various alternatives on how their bills are paid.

	Training Group (n=9)	Control Group (n=10)
ATM	1	1
Staff	1	1
Family members	2	2
Bank	1	5
Do not know	4	1

Responses in the post-test suggested that training group participants had acquired some knowledge of these topics. All participants first were given a simple counting task to see if they could count money. For instance, they were asked to count out $30 when given several $10 notes. Table 6 presents the results, and shows no great difference between the groups in two tasks, but that the control group actually did much better in one task.

Table 6

Number of participants able to correctly count out various sums when given various denominations of notes in the post-test

Task	Training Group (n=9)	Control Group (n=10)
Count out $30 in $10 notes	6	5
Count out $100 in $20 notes	3	6
Count out $100 in $50 notes	4	4

Table 7 presents answers to questions about banking. The table shows that most training group participants had learned about the non-altruistic nature of banks. In the pre-test, most had stated that the bank would give them all the money that they wanted, but only two participants did so in the post-test. Most training group participants understood that their

pay went into their bank account, but interestingly enough, so did most control group participants. Training group participants also could deal better with basic banking concepts such as deposit, withdrawal and credit card. Table 7 shows that more could define these terms than could in the control group. More in the training group could explain that a credit card is not directly attached to a bank account, that the user must sign a credit card receipt, and that he or she eventually will get a bill.

Table 7

Number of participants making a statement or answering a question in a particular way. N/A indicates that the question was not asked in that condition.

Question/Task	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Stated bank would give all money needed	8	2	8	4
Where does bank get money it gives you				
Pay/pension	2	0	3	0
Family	2	0	4	0
Miscellaneous	3	0	0	0
Do not know	2	0	3	0
Could state where pay goes	0	9	0	9
Could define deposit	N/A	8	N/A	6
Could define withdrawal	N/A	9	N/A	4
Could define credit card	N/A	6	N/A	4
Could state ATM as way	N/A	8	N/A	5

to take money from account

To test whether training group participants had gained some notion of budgeting, in the post-test, participants were asked to name a short-term goal and how they might achieve that goal. Table 8 presents the results. All nine training group members could name a short-term goal, while only three in the control group could do so. All training group members could describe how to save for that goal, while few control group members could.

Table 8

Number of participants who could name a short-term goal and could describe how to save for it in the post-test

	Training Group (n=9)	Control Group (n=10)
Name goal	9	3
How to meet goal	9	3

A number of questions tried to gauge what knowledge the training group participants had acquired about retirement. In pre- and post-tests, participants were asked to define the term "retirement", to state the age at which one retires, and to state whether they had plans for retirement. Table 9

presents their responses. In the pre-test, seven members in each group could

define retirement, and in the post- test all in the training group could do so.

More participants in the training group also could state a retirement age.

When asked whether an individual should have plans for retirement, six

from both the class and control groups answered "yes". When asked if they

actually had plans for retirement, only two from each group answered "yes".

Table 9

Number of participants able to answer various questions about retirement in

pre and post-tests. N/A indicates that the question was not asked in that

condition.

Question	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Can define retirement	7	9	7	7
Can state retirement age	4	6	4	2
Should have retirement plan	6	6	N/A	N/A
Do have retirement plan	2	2	N/A	N/A

Table 10 presents answers to the question of how they were going to fund

their retirement. All training group members could state that their retirement

would be funded by a pension, while control group members gave a variety of responses.

Table 10

Number of participants in each group stating that they would have a particular source of funds in retirement

Source	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Pension	0	9	2	4
Family	5	0	1	0
Bank	1	0	4	3
Staff	1	0	1	0
Do not know	2	0	2	3

Table 11 presents data on attitudes towards impending retirement. After the course, most training group participants reported being happy about the prospect of retirement. However, two more reported being sad, perhaps because they now knew more about what was involved in retirement.

Table 11

Attitudes toward retirement expressed by participants

Attitude	Training Group (n=9)		Control Group (n=10)	
	Pre-test	Post-test	Pre-test	Post-test
Happy	7	6	5	7
Sad	1	3	1	1
Do not know/	1	0	4	2
Unclear response				

DISCUSSION

Overall, participants in the training group showed some increases in knowledge in the relevant areas. The training course evidently was improving their knowledge. However, in some cases the data are difficult to interpret because the control group members also were showing increases in knowledge. For instance, Table 3 shows that control participants could name more types of volunteer work. There are several interpretations. One is that training and control group members interacted frequently outside the class and the training group members may have been passing on their new knowledge. Of course, it was not practical or ethical to separate the groups completely for the eight weeks. From a purely educational point of view, this interaction is fine but for the study purposes it makes the results more difficult to interpret. Also, participation in Study 1 and in the pre-test of Study 2 may have prompted more interest about the topics, which participants pursued on their own. Another interpretation is that the result is due to the general difficulty of interviewing persons with an intellectual disability and determining just what they do know. Only two participants could write, and only one could do so well. They may have been confused about earlier answers.

However, the author's overall subjective impression was that the participants enjoyed the training sessions and benefited from them.

CHAPTER Ten

GENERAL DISCUSSION

The overall results may be summarised as follows. Study 1 found that most of the 60 participants had solid concepts of work and leisure and had a strong work ethic. Most knew that leisure time is an important restorer of mental well-being and that one's work and leisure lives need to be balanced. Most were quite happy with their current work and leisure activities and did not particularly want to know more about work and leisure in general. However, there were some gaps in their knowledge of work and leisure. In the work arena, most had little understanding of volunteer work and of occupational status. Knowledge of retirement and the need to prepare for it also were very limited, with some participants indicating the desire to learn more about retirement. Knowledge of handling money and banking in general were also generally poor, although only two participants stated that they wished to learn more about these topics. This data provide an intriguing and novel insight into how persons with an intellectual disability view the important domains of work, leisure and retirement.

Participants in Study 1 typically reported much satisfaction from their current work and most did not want different jobs, even more prestigious jobs. Perhaps this general satisfaction could be partly due to their apparent lack of knowledge about occupational status. Status striving is endemic in the working world. Workers in low prestige occupations typically must work very hard and may have little control over their working time. Consequently, they may be more likely to be dissatisfied with their jobs. This present finding that persons with an intellectual disability typically enjoy their work is consistent with that of some other studies (Jiranek & Kirby, 1990; Ashman et al, 1995b). Test et al (2000) found that individuals in their sample were satisfied with their supported employment situation and their specific jobs. As mentioned previously, Edwards (1995) queried whether persons with an intellectual disability do have a work ethic, but Study 1 confirms that they do.

It is interesting that participants in the present study value their jobs and have a strong work ethic, yet still appreciate the value of leisure. They tended to choose their own leisure activities and to participate in them with other persons much of the time. Socialising with friends and family plays a major role in their leisure lives. This finding about satisfactory leisure lives contrasts with the results of some other studies (e.g. Bigby, 1992, 1998; Ashman & Suttie, 1996). For instance, Mahon (1994), in a United States

study, found that many persons with an intellectual disability were socially isolated and needed more community involvement. One possible reason for the difference between the latter study and the present study might be the younger average age in the present study. A second might be that, as mentioned above, Sunnyfield Homes organises many leisure activities for its service users. In addition, some participants still lived with their parents, who helped arrange their leisure activities. Finally, Australia has extensive welfare services for persons with an intellectual disability, including ample funding for various leisure activities (Moyle & Gibson, 1997).

The findings from Study 1 found that participants typically knew little about banking and budgeting. Most participants queried about money matters felt that the bank would give them all the money they wanted. Many understood that their pay went into a bank account, but beyond that had little knowledge of banking. The concepts of both banking and budgeting were taught during the class, each participant learning that he or she had a separate bank account that they could access, but that also had limits. For class members, it was up to a carer to access their bank account and provide money when needed. Participants also typically did not manage their own money; carers did instead. During the eight-week course only the most elementary aspects of budgeting could be covered, that of the short-term savings goal. Much further education in money matters is needed for the

intellectually disabled if they are to be able to make informed choices and decisions regarding their day-to-day life and their retirement. Indeed, Browder & Grasso (1999) recommended a continual program through their working lives to facilitate an ever expanding understanding of money management and planning for retirement.

The present finding of poor knowledge of retirement is consistent with some previous studies (e.g. Ashman et al, 1995b). In many cases, participants had not even thought about impending retirement and the need to plan for it. Many participants had difficulty with the concept of ageing, and had trouble visualising their own ageing and eventual retirement (also see Lifshitz, 2000). Many apparently did not really view themselves as growing older and eventually needing to retire.

In Study 2, an eight-week education program partly based on the findings of Study 1 and using a conceptual approach to education was developed and taught to nine participants. It was clear that the program was at least partly successful. Some participants acquired more knowledge about banking, volunteer work, and retirement, for example. However, no statistical analysis was performed on the results so the conclusion is not firm. The control group also showed increased knowledge of some areas, which can be interpreted in various ways, as was mentioned earlier.

SOME LIMITATIONS OF THE PRESENT STUDY

However, the present study has a number of limitations. Study 1 has several limitations. Although the sample size of 60 participants was much larger than that in many previous studies, which often have fewer than ten participants, most participants worked for one organisation. This might bias some results, especially concerning the domain of leisure activities. As mentioned, Sunnyfield is particularly adept at providing leisure and work activities for its clients and in aiding their access to services, such as providing a bus to venues for various activities. The sample was one of convenience rather than a random one, but a random sample is very difficult to obtain. In addition, the main aim was to determine what a specific group knew about the key concepts and run an education program based on that information as a demonstration study.

Another limitation of the present study is that the data could not be analysed by degree of intellectual impairment. As mentioned, specific IQ scores were not known. One would expect that this would be an important factor in conceptual learning. Further research with might examine this question.

Another limitation of the present study is that the complex question of how participants came to hold the specific concepts of work, leisure and retirement that they do was not addressed. There are many possibilities for how they might hold their particular concepts. For instance, participants have gone through many different life experiences, which can affect the information contained in their concepts. Sharing a house with a retired person for years should create a richer concept of retirement than that held by a person who never has any contact with retirees. However, the question of how people come to hold the concepts that they do is very complex (Howard, 1987) and is not greatly relevant to the main purpose of this thesis: of improving educational efforts for persons with an intellectual disability. The key focus is on what participants already know and how to use that as a basis for improving educational efforts. Also, for the same reason, this study did not look at the concepts of work, leisure and retirement held by persons without an intellectual disability. These concepts in non-disabled persons would likely be much richer, but that is not directly relevant to the key concern of the present thesis. No such control group really was necessary for Study 1.

A related issue is the number of non-responses to some questions in Study 1. Some of the questions might indeed have seemed quite difficult to persons with even a mild intellectual disability and were inserted to probe

the limits of their concepts. Concepts develop, and some people have much richer concepts of such categories as galaxy or subatomic particle than others. Most respondents were able to answer most questions about work and retirement issues and there were further checks on their knowledge, such as the initial classification task and asking participants in some cases to provide further instances. Non-response may indicate a complete lack of understanding of the question asked, or just of the concept, and it was not always possible to distinguish between these. Most questions were framed so that knowledge of the concept of concern was paramount; e.g. "What does community mean to you?"

Study 2 has a number of limitations, which may affect interpretation. The first limitation was the small sample in the training group, limited by the small physical space available to run the course and because only one instructor was available. The sample size was too small for any meaningful inferential statistical analysis, also given the large number of comparisons made in the data. A second limitation, mentioned earlier, was that training and control groups interacted. All worked in the workshop at Sunnyfield, and members of both groups might even work side by side during the day. At breaks for lunch and tea, the entire staff congregated in the canteen, with much friendly talk amongst themselves. Many lived in the Sunnyfield group homes, opening up more possibilities for information sharing. As mentioned,

this knowledge sharing is fine for purely educational purposes, but it makes data interpretation more difficult. A related problem is that all participants took the pre-test and it was possible that they then tried to learn more about subjects that they were unsure of, on their own. The participants had a strong desire to please, and once a new topic was introduced on a test, they wanted to appear as competent on the subject as possible. Again, this is fine for educational purposes but it makes the findings more difficult to interpret.

The present thesis also did not look in detail at whether individuals in the training group actually applied their knowledge acquired in the course to the real world. The aim of teaching concepts such as those taught in the present study is for the participants ultimately to apply them to their own lives, such as in making informed, pertinent decisions regarding their own retirement. It was not possible to gauge such an application or to carry out a long-term follow-up of knowledge retention. However, future research might do so. Given the difficulty with which those with an intellectual disability have in generalising specific concepts taught mentioned earlier, more extensive training might be needed to ensure extensive and continuing transfer to the real world.

SOME IMPLICATIONS FOR RETIREMENT ISSUES

Persons with an intellectual disability are living longer and the impending retirements of so many is causing concern amongst governments

and welfare agencies. With Australian government cutbacks in many welfare services and the increasing proportion of retirees in the population in future decades, the problem may become quite serious. Governments and welfare agencies need to plan. Affected individuals also need to plan for retirement to make their transition to retirement smoother and their retirement years more satisfying. "Successful ageing" is needed (Bigby, 2004). Bigby notes the need for lifestyle planning, planning for housing and support, for health, and the importance of retirement planning well in advance of actual retirement. Individualised planning, flexibility and choice are needed for successful programs (Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004). Bigby et al (2004) also noted that many service providers had little understanding of the diversity of the ageing process and notions of healthy ageing and many had limited expectations of older people. Such staff also may need specific education programs.

To ensure effective individual retirement planning and for agencies to offer appropriate services and choices, the needs and desires of the intellectually disabled have to be known. To facilitate this, an individual with an intellectual disability needs a sound concept of the ageing process and of retirement to make his or her choices and wishes known. Most participants in the current study lacked a solid concept of retirement and had done no retirement planning. This finding, along with that of other studies

(e.g. Bigby, 2002; Ashman et al, 1995b), suggests the need for large-scale educational efforts for the affected population. The present conceptual approach should be particularly useful. Educational efforts may be done over a long period, so that affected people feel comfortable with the subject, and are willing to contemplate their own retirement. An encouraging sign from the present study was that once the participants in this study were given preliminary information on retirement, they expressed a desire to learn more about it.

THE GENERAL VALUE OF A CONCEPTUAL APPROACH TO EDUCATION

Several authors have made the call to base education in general largely on concepts (e.g. Hirsch, 1987; Howard, 1987). Hirsch criticised the then popular educational doctrine of favouring the teaching of "process" (teaching abstract thinking skills) over "content" (teaching factual knowledge). Hirsch drew on a large amount of research in cognitive psychology which suggests that expertise, the ability to perform well in a particular domain, is domain-specific and is based largely on a great deal of domain-specific knowledge (also see Howard, 1995). Expertise in chess, for example, depends on much domain-specific knowledge (e.g. of piece configurations and basic combinations), and such knowledge may transfer little to other domains. In practice, teaching abstract thinking skills that supposedly can be used in almost any domain may not be very useful because expertise is domain-specific (Hirsch, 1987). Such general skills are difficult to apply. Therefore, teaching in a domain should involve a lot of specific knowledge in a given domain and that knowledge should be organised around key concepts.

The present study illustrates the value of taking this conceptual approach to education of persons with an intellectual disability. The approach involves a focus on domain-specific knowledge and determining

what concepts the participants already hold in a given domain and how they use those concepts to view and deal with the world. That knowledge should be the starting point of instruction. More knowledge can be added to their existing concepts and also participants can be taught more adequate concepts which they can use to deal better with the world. Several advantages of this conceptual approach are apparent from the present study. First, a conceptual approach is efficient. Study 1 showed that relatively little instruction needed to be directed at the work and leisure domains with the participants, but that much was needed on retirement and money management matters. Second, the approach emphasises what important concepts the individuals do need to be taught, such as banking, budgeting, and volunteer work, and what component concepts needed to be taught. The training program was organised around these concepts. When the concepts were acquired, the participants could use them to deal more adequately with the real world; e.g. in planning for retirement.

A conceptual approach also emphasises that concepts may develop with time and experience, often becoming richer and more useful in interaction with the environment. This suggests that concept teaching should be a continuing educational process, especially with persons with an intellectual disability.

This general conceptual approach can be applied to teaching other important practical concepts to persons with an intellectual disability. Some examples are basic civics concepts such as voting, many concepts applying to aspects of social behaviour, of sexuality, and of health, for instance. Questions that researchers might address concern the concepts that persons with an intellectual disability hold in these domains and how they might use them to make sense of the world and guide their action in these domains. How rich are their concepts; e.g. how much information do they contain? Do persons with an intellectual disability have many misconceptions that might need correction, just as many non-disabled persons do? For instance, misconceptions about sexuality are common (e.g. that a woman cannot become pregnant when having sex for the first time, etc.). What additional concepts can they learn? At what ages are these concepts best taught? The same basic method can be used as in the present thesis; interviews to determine existing concepts, determining knowledge gaps, and arranging a conceptually based curriculum to teach more adequate concepts. As mentioned earlier, just analysing a curriculum into component concepts can be very revealing to the instructor. Further instruction might aim at getting participants to generalize the newly acquired concepts, for instance by programming real world practice in their use.

Of course, not all education involves teaching concepts, however. Specific skill training also is involved, as mentioned in Chapter 1.

FURTHER RESEARCH

The potential value of extending the current general conceptual approach to other domains with persons with an intellectual disability was discussed above. This section will suggest some other possible avenues for future research.

<u>Changes in working life</u>

Chapter 1 reviewed some research on various recent changes in working life in Australia, changes which are inducing more stress in many workers and provoking such responses as a downshift and/or a sea change. It is not clear if many persons with an intellectual disability in the work force also are suffering such stress. Participants in Study 1 mainly reported being quite happy with their working lives but many did work in a sheltered workshop. Some persons with an intellectual disability do hold regular jobs and it is an interesting question whether changes in the organisation of work are creating similar stresses in some of them and a wish for downshifting. Further research might investigate whether this is occurring. If it is, educational efforts might focus on ways of dealing with workplace stress and also on teaching such concepts as workplace stress, downshifting and making a sea change.

<u>Other concepts held by persons with an intellectual disability</u>

Concepts are the building blocks of cognition and learning and are crucial to dealing effectively with the real world. Chapter 1 reviewed some relevant studies on various concepts held by persons with an intellectual disability but not a great deal of research really has been done in this area. Many more concepts could be examined, and not just the more practical ones mentioned above. As mentioned, relatively little work has been done on the self-concepts of persons with an intellectual disability (e.g. Plesa-Skwerer et al, 2004), and this is another avenue for further research. The methodology of Study 1 of the present thesis could be used to examine many more concepts held by persons with an intellectual disability and how they use them to make sense of their world.

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The questionnaire used in Study 1.

Name

Address

Phone

Date of birth

Country of birth

Educational level

Sex

Work history

  First job

  Current job

  Types of work done

  Ranges of pay

Daily activities

1. Some examples of people doing daily activities include riding a bike, swimming, cleaning the house, office work, gardening, shopping and watching television. Which of these or any other activities you perform, would you consider work? Which would you consider leisure?

2. For which of the work activities are you paid?

3. What would happen if everyone stopped working?

4. Where would you get money to pay for things if you did not work?

5. If the government pays you a pension, should you have to do some work for it?

6. What do you think about a:

    a. layabout

    b. someone who calls in sick once a week and goes to the beach

    c. someone who does this once a month

    d. someone who does this very occasionally?

7. Do you think everyone should work?

8. What benefits do you get from work?

9. Your own work experience:

    a. What type of work do you do?

    b. What do you gain from it?

    c. Would you like to work more hours? Why?

    d. Would you prefer to do a different job? What job?

    e. What keeps you from working more or at all?

10. Would it be OK if you did not work at all?

11. What does work mean to you?

12. Should you always be paid to work?

13. If you are currently on the dole, should you be required to do some type of work to collect it?

14. What is volunteer work?

15. What do you think of people who do not work?

   a. What do you call these people?

16. What do you think of a person who chooses to go to a movie instead of going to work?

17. What benefits do you receive from working?

Let's look at the examples of fun/leisure that you chose as leisure activities.

1. What makes these activities leisure and not work to you?

2. Would everyone see activities such as gardening, swimming, reading or computer programming as leisure? Why?

3. What leisure activities do you currently participate in?

4. What additional leisure activities would you like to participate in?

5. What stops you from participating in the additional leisure activities you would like to participate in?

6. Do you always choose the leisure activities you currently participate in?

7. If you do not choose the leisure activities you currently participate in, who does?

8. How much time do you spend on leisure activities each week?

9. Would you like more time to participate in leisure activities?

10. Do your leisure activities involve others, or do you do them by yourself?

11. If you do these leisure activities with others, who does them with you?

12. What kinds of activities do you do in the community?

13. What does community mean to you?

14. What training would help you participate in more meaningful leisure activities?

Retirement
1. Do you know anyone who has worked for many years and no longer works? Tell me about these people.

2. Will this eventually happen to you?

3. Do you think there will ever be a time in your life when you have more time for leisure activities?

4. What is retirement?

5. What sorts of things do retired people do?

6. Do you look forward to retirement when you do not have to work?

7. How old is a person when he/she retires?

8. How old are you?

9. How many years will it be before you retire?

10. How do you see your life now between work and leisure?

11. How do you picture your life after you retire?

12. What training would help you better prepare for retirement?

Schematic overview of the curriculum material used in Study 2. This material was taught with exposition, discussions, questions, and various other methods.

LIFE CYCLE

Name

Birth date

Address

Phone

Childhood (Birth to age 15)

Place of birth   Picture as child

Names of parents:

  Mother

  Father

Occupations of parents:

  Mother

  Father

Names of siblings: <u>Older</u>   <u>Younger</u>

  Sisters

  Brothers

Where did you live as a child?

Whom did you live with?

What do you remember about your early schooling?

What family activities did you do?

Which of the family activities listed above did you enjoy doing most?

High school and transition to work

Where did you go to high school?   High school picture

Type of program:

Favourite activities in high school:

Did you play sports?

If so, which sports did you play?

What did you do for fun?

With whom did you do these fun activities?

Have you continued doing any of these fun activities as an adult?

If so, which fun activities?

Where did you live during high school?

With whom did you live during high school?

What work experience activities did you do in high school?

Which work experience activity did you enjoy most?

As an adult, did you end up with the job in your favourite work experience?

Adult life- the working years

Picture as an adult

Is this the same person as the picture of the child at the beginning?

Do you look different?

How have you changed?

Why have you changed?

As you get older, do you think you will change more?

Do all people change as they get older?

Where do you live now?

With whom do you live?

Do you like your present living arrangements?

How does your present living arrangements differ from you childhood living arrangements?

Who is responsible for the cooking and cleaning in your present living arrangements?

Who did the cooking and cleaning when you were a child?

Do you get to choose what and when you want to do fun things as an adult?

Did you as a child?

What fun things do you chose to do as an adult?

What are your responsibilities at work?

Have you ever done volunteer work as an adult? (This does not include work experience)

What kind of volunteer work would you like to do?

How could you find out what to do to get involved in volunteer work that you like to do?

Are you happy with your adult leisure activities?

What are your adult leisure activities?

Have your leisure activities changed since you were a child?

Why?

Do you think they will change in the future when you get older?

Why?

How do you pay for your leisure activities?

Who is responsible for your money?

BANKING AND BUDGETING

What happens to your pay cheque if it is direct deposited?

Sunnyfield puts the amount (deposits) the amount you have earned into a bank account that has a special number only you can use. No one else has this bank number.

Your pay is deposited into your account—it is put there for you to decide how to use.

You can only use the money deposited into your account and no more.

If you deposit money into your account, other than pay, you have to fill out a deposit slip. Here is an example—you fill out several practice deposit slips.

To use the money you have deposited into your bank account, you have to withdraw it.

You can only withdraw from your own bank account.

You can only withdraw from your bank account the amount of money you have in it.

You can withdraw your money in several different ways:

1) Use an ATM card for which you need a automatic teller machine and a special code only you know. Do not give this code to a stranger.
2) Fill out a withdrawal form (a sample is provided with several to practice on) and take it to the teller where the teller gives you the cash.
3) Fill out a cheque for a company you do business with to cash. The bank gives them the money.

To have a bank account, you usually have to pay bank fees which act like a withdrawal to your account every month. The amount of the bank fees varies.

If you want to set up a bank account, there are special workers in the bank who can help you fill out the forms and assign you a special number.

Value of money

What can you buy for $10?

What can you buy for $100?

What can you buy with $10,000?

What does it cost to rent a one bedroom unit?

What does it cost to buy a day's travel on public transport?

What does it cost to buy a CD or rent a video?

What does a night out at the RSL cost?

What does an outfit of clothing (shirt, pants, underwear, socks, shoes) cost?

Budgeting –Spending plan

Basic definitions

Income—any money that's yours. This money can come from your pay packet, pension from the government, allowance from parents/family, etc.

Expenses—any money you spend for goods or services. Examples include rent, movies, transport, going out to eat, shopping for clothes and renting videos.

Savings—money you decide not to spend and put in a special place to keep for use later. You can use saving to pay for a special trip, a new TV, etc.

Goals—Specific things you want to save for over a period of time (weeks, months, years). They cost too much to buy out of one pay cheque.

RETIREMENT

Will you still be you when you retire?

What do you think you will look like?

In how many years will you retire, assuming you retire at 65? (65 minus your present age)

How will you spend your time?

Will you still have a job?

Do you think you will work as much as you do now or less?

Would you like to do a different type of work? What?

How would you get the training for a different type of paid work?

Do you think you would like to do volunteer work?

If so, what type of work?

Will you need further training or experience to do your desired volunteer work?

How would your leisure activities change?

Will you change physically as you age? Will this affect your leisure activities?

Do you think you'll have more or less money?

Do you think your interests will change? (Have they changed since you were a child?)

Do you think you'll always be able to get to your desired leisure activities?

What type of group activities would you like to participate in? Examples might include clubs, special trips to other places in Australia or overseas, etc.
How will you pay for your retirement?

Do you think the government will continue paying you a pension?

Do you think you will save any money for retirement (superannuation)?

Do you plan to continue to work part time?

Questions on the pre- and post test questionnaires used in Study 2

Name

Address

Phone

Date of birth

Sex

Date and place of interview

Comments

What type of work do you currently do?

Do you like it?

What is volunteer work?

Do you get paid to do volunteer work?

Have you ever done volunteer work? Type?

Would you like to do volunteer work in the future, especially- when you're retired?

What type of volunteer work would you like to do? Some choices include gardening (bush care), volunteering in old age home/hospital, being a member of Merry Makers, helping with the Sunnyfield Great Duck Race, taking care of injured animals or at the RSPCA.

Where would you find out about doing volunteer work?

What did you do during the day when you were a child and in high school?

What do you do during the day now?

Are you the same person you were as a child?

How have your looks changed since you were a child?

What were your leisure activities in high school? (Name three)

What are your favourite three leisure activities now?

Why have some of these activities changed?

How do you think you will look when you are retired?

What three leisure activities will you probably do when you are retired?

What does it mean to be retired?

At what age do most people retire?

Where will you get money when you are retired?

Have you made any plans for retirement?

Where will you live when you're retired?

How do you feel about eventually retiring?

Where does the money go that you earn from Sunnyfield so that you can use it?

How does the bank know that the money belongs to you and not someone else?

Which slip would you fill out to put money into the bank?

What information needs to be on this slip?

Which slip would you use to take money out of the bank?

What information needs to be on this slip?

How else could you take money out of the bank?

How is a credit card different than an ATM card?

Can the money you have in the bank eventually run out?

Will the bank keep giving you all the money you want even if you have no money in your account?

Give me an example of a short- term budget goal?

How can you save for this?