Preparing Adults with Intellectual Disabilities For Later Life:

Optimizing Choice-Making

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To old friends

Contents

Introduction

Themes and structure of the dissertation

Over the last years the world has seen a growing number of persons who live far into their seventies and even eighties. Not only men and women in the society at large are preparing themselves for a long and healthy life, but also persons with Intellectual Disability (ID) want to live a long life with as little physical difficulties as possible. Unfortunately, because of historical circumstances many persons in the latter group have not had the same opportunities to gain knowledge on successful aging as people in the general population have had. Research that will be presented in Chapter I shows the overall importance of knowledge as a protective factor that can help a person to age successfully and ways in which one can influence this process.

For many years, persons with ID might not have had the chance to shape their own world, to make their own choices. Many older people with ID - both in the US and in Europe - have lived in large institutions in which choice making was a rare commodity. Thanks to the normalization and integration movement begun in the late sixties and early seventies of the past century many of the old institutions have been closed down and many persons with ID have moved into community dwellings. Within the fabrics of their community most persons with ID now have more opportunities to create a life according to their wishes and choices.

Compared to younger persons with ID, older persons with ID still have only little opportunity to influence their future. When reaching older age, many have lost family members, friends, work, some skills and stamina. They often did not learn to compensate for these losses and plan for later life. The central purpose of this dissertation is to examine the impact of an education program for older adults with ID, called “Person Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994).

In the first part (Chapters I - III) theoretical, historical and health notions underlying this program are discussed; whereas in the second part (Chapters IV - VIII) detailed information will be presented about the adult education program and research findings in the US and the Netherlands, evaluating systematically participants’ gain of knowledge and amount of satisfaction.

The program “Person Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” - that lasts about four months, with a two-hour lesson each week - teaches older people with ID the important issues of later life (see Chapter VI), like how to make choices, the importance of physical exercise and eating healthy foods, possible leisure and recreation activities, how to make new friends and keep old ones, options for early retirement or part-time work, various types of living arrangements, and how to maximize the student’s influence on his or her Individual Service Plan. To make things more concrete two field trips are included in the curriculum: one in connection with the lessons on leisure and recreation activities and one to show participants some possible future living arrangements.

The original idea of the authors of the program was to include in the curriculum a part on death, loss and dying. Because of the sensitivity of the subject and because individuals with ID differ greatly with regard to their ability to conceptualize death and dying and in their personal experiences, they decided against it and created a

separate program: “Person-Centered Planning for Later Life: Death and Dying - a Curriculum for Older Adults with Intellectual Disabilities” (Sterns et al., 1999). Apart from being an instrument to actually teach persons with ID about death and dying - teaching being the goal of adult education - the course also provides ways and means to help persons with ID to learn to cope with past or present losses.
The program starts with an introduction of the four basic concepts underlying an understanding of death and dying - causality (knowledge of the causes of death), finality (the understanding that all life functions cease with death), inevitability (the understanding that all living things eventually die) and irreversibility (knowledge that, once dead, a deceased person cannot return to life). Later lessons teach participants how they can cope with loss and how to show sympathy to the bereaved family, how to behave during wakes and memorial services and how to plan one’s own funeral service. The program closes off with a field trip to a place of participants’ choice that has to do with death or dying.

The program “Person Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation” and the program “Person-Centered Planning for Later Life: Death and Dying - a Curriculum for Older Adults with Intellectual Disabilities” build on the concepts of life-span development and successful aging - to be expanded upon in Chapter I - and the concepts of normalization, integration, empowerment, choice-making and person-centered planning - to be discussed in Chapter III. Older persons with ID are specifically challenged in maintaining good health and quality of life in avoiding disease and other health risks. Chapter II highlights these risks.
In Chapter IV the ideas behind adult education and the program “Person-centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” will be described as well as the differences between the index groups in the US and in Europe. The research findings of the American evaluation study will be summarized and discussed in Chapter V.
The main research questions and the research findings of the Dutch training program will be presented in Chapter VI.
For the same - historical - reasons not only persons with ID need some training to learn to prepare themselves for later life; persons with long-term mental health problems also meet the same obstacles. Chapter VII shows the experiences and results of teaching the program to older persons with chronic mental health problems, some of whom had ID as well.
In the first part of Chapter VIII an outline of the differences and similarities between grief responses in persons with and without ID is given; the second part deals with the content and results of the training of the program “Loss, Death and Dying - a Curriculum for Older Persons with ID”.
A general discussion, concluding remarks, and recommendations for scientific research, policy makers and people working in the field will be presented in Chapter IX.

Defining Aging and Intellectual Disabilities

Aging

In trying to understand the concept of aging it is good to realize that there is a biological, psychological and social aspect to this phenomenon. In biological terms one can say that from a certain time on, an individual becomes frailer and eventually will die. In sociological terms in the course of his or her life a person will adopt other or new roles more in line with the way his or her generation passes through time. In psychological terms over time an individual develops a decreased ability to cope with his or her surroundings and becomes less apt to self-regulate.

From the biological perspective - that long has been the predominant perspective - a person is born, lives and dies at a certain moment in time. It is a story of decline, an inherent process in which the many changes a person goes through in his life are largely seen as irreversible, universal, unilateral, highly predictable and hardly susceptible to influences from the outside world. There seems to be some uneasiness with this viewpoint though, as biological researchers also point out that individual choices can make a difference, for instance maintaining a healthy diet and doing a fair amount of daily exercise. This cloud of doubt does not shade the mind of biologists in the respect that most of them agree to the fact that all species have a maximum life span, given as it were in their genes. With the present state of knowledge this span for humans would be 110 to 115 years of age.

From a sociological viewpoint it has always been very important to look at the birth cohort to which an individual belongs, as this has great influence on how people age. Not only the ways in which children at a certain time were fed or educated, but also certain major events in the life span of a cohort - like wars - have major influences on the life chances of that cohort. Sociologists also have studied the many roles a person fulfills during his or her life and how changing roles affect functioning in society. A famous example of such a change in status and role is a woman whose children have left the house and whose sole occupation is caring for her husband and her house - the famous “empty nest”-situation.

For long, psychology has focused on the developing person, from infant to child, over adolescence into adulthood. For a long time it stopped there, as after adulthood only decline was expected, which was considered to be an uninteresting subject to study. Over the last decades however an enormous body of research (Baltes & Baltes, 1990; Schaie, 1983, 1989, 1994; Birren and Schaie, 2001) has shown that life does not stop at forty - or even fifty - and that the concept of (successful) aging is worth studying. Not only because of the number of aging people and therefore their grown visibility - two thirds of the populations in Western, industrialized countries now reach the age of seventy and over - but also because of this paradigm shift. According to World Health Organization data (WHO, 1999) the figure of - worldwide -580 million people aged 60 years or older in 1999 will rise to 1,000 million by the year 2020 - a 75% increase compared with 50% for the population as a whole. Because of a sharp decline in premature mortality from infections and chronic diseases life expectancy has risen and is expected to go on rising in almost every part of the world. A further increase might be expected from improvements in sanitation, housing, and nutrition, a wider application of vaccinations and a greater availability of antibiotics. It is expected that from the 1,000 million older persons in 2020, over 700 million will live in the developing world.

More and more researchers are studying how these biological, physical, social and cultural influences interact with each other in the process that is called aging. There are many perspectives from which one can look at the concept of aging (Rüberg, 1987).

There is one's chronological age - how many years and days a person has lived, an administrative age - to be used in statistics - and a legal age -, which pertains to one's legal rights and responsibilities at a certain age.
A person can also be characterized by mental age - what knowledge did one acquire during one's life -, by religious age - what religious beliefs a person holds -, and by historical age - what happened in the world a person lived in. In this respect one might think of the prevailing policy in Nazi Germany to kill psychiatric patients and persons with ID and the impact that these killings still has on the minds of many people with ID now living in Germany and Austria. In the twelve years of the Nazi regime almost all persons with ID were killed, which is still reflected in the figures of today: in the late nineteen eighties in sheltered workshops in Western Germany only 625 persons - 323 females and 302 males - were older than 60 years (BIM-Extra, 1988).

Psychologists have long focused on the negative rather than the positive aspects of aging. They noticed that older people, for instance, tend to turn their attention away from other people and activities outside their home and retreat to a smaller and calmer inward world (termed "disengagement"), which was considered to be a negative trait. Baltes and Baltes (1990) have proposed that although it is true that older people have less social contacts than younger people, the quality of these contacts is much higher and older people tend to rely heavily on the meaningfulness of these contacts. Although older persons may have lost certain social roles and the see fewer people, these losses can be compensated by the highly rewarding relationships they maintain with selected other persons. Older persons certainly loose some faculties, but they can compensate for these losses by "selective optimizing", which means that having lost a certain faculty - e.g. hearing and visual impairments that leave them feeling uncomfortable in large crowds - they tend to compensate for this loss by seeing loved persons in the intimacy of their chambers. Psychologists now have turned their eye away from the loss-side of getting older - the irreversible downhill road of decline and loss of dignity - and are starting to look into the reasons why so many older people live a long and happy life. In other words they study the determinants of successful aging.

Intellectual Disability

The term "Intellectual Disability" (US) is a relatively new term. For long the expressions "Mental Retardation" or "Mental Handicap" (United Kingdom) were used, but for reasons explained below, people in the field now prefer the term Intellectual Disability (ID).
"Mental Retardation" in itself is only one term in a long line of words that were meant to indicate the condition in people that had a lower than "normal" intelligence. At times these people were called oligophrenic, imbecile, feeble minded, mentally defective or mentally deficient, mentally subnormal or - until recently - mentally retarded. In their everlasting effort to find new, less obtrusive or less offensive terms people in some countries have come to use terms like "developmental disabilities" or "learning disabilities", terms that create confusion in other countries. The term "learning disabilities" for instance, often used in the United Kingdom for people with ID has quite another meaning in the US and on the European continent. There the term refers to children with a normal intelligence but with difficulties in reading and/or writing, for instance dyslectic children.

Until the beginning of the 1980's the general definition of intellectual disabilities was based largely upon the performance of an individual upon a standardized intelligence test, given by a trained professional, resulting in an Intelligence Quotient (IQ) score. ID was generally thought to be present if an individual had an IQ test score of at least two standard deviations below average, resulting in a score below 75 - 70 points. Nowadays, people involved in the field of ID - clients, parents and professionals alike - feel that more aspects should be looked upon before a person can be labeled a person with intellectual disability: there must be concurrent impairments in adaptive behavior, defined as standards of personal independence and social responsibility expected of age, and cultural group (AAMR, 2002). Most importantly, these characteristics must manifest themselves during the developmental period, which is between conception and eighteen years of age.

The newest AAMR definition of intellectual disabilities offers the following broad perspective (AAMR, 2002):
"Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.
A complete and accurate understanding of mental retardation involves realizing that mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports.
As a model of functioning, it includes the environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcome of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being."

An important difference between the "older" definition (AAMR, 1992) and the "newer" AAMR definition is the greater emphasis that is placed upon the supports a person with ID could/should get from its environment: the ecological perspective, a fruitful concept on which I will expand in Chapter II. In this different perspective on ID a person is no longer "a bundle of deficits", often living in an institution, but a respected member of society with limitations but also with strengths.

For practical purposes and for determining what supports a person might need - psychologists and educators have long used the following subdivision in four categories of ID: mild, moderate, severe and profound.

- Persons with mild mental retardation (IQ 50-55 to approximately 70) can be expected to achieve academic competence and literacy. They also have good potential for competitive employment and independent functioning. The majority of persons with mental retardation fall in this category.
- Persons with moderate mental retardation (IQ 35-40 to 50-55) may acquire survival and functional skills. Some gain employment in competitive settings while others work in supported settings. They master self-help skills and typically live in supported settings.
- Persons with severe mental retardation (IQ 20-25 to 35-40) may achieve some functional skills (toileting, self-feeding, dressing). They will need varying degrees of assistance with daily activities. Employment is possible and is typically in supported settings.

- Finally, persons with profound mental retardation (IQ below 20 or 25) may achieve such skills as attending to sound sources and cooperating with caregivers, but for the most part they are totally dependent on others and employment or training is not likely.

Apart from the changing paradigm on intellectual disability the other major influence on redefining the concept of ID is the growing number of old and older persons with ID, caused by improved medical care and better socioeconomic circumstances. Their growing numbers have serious implications for the specialized - and generic! - care and service systems. No longer is “school” - and everything that is connected with it - the major focus of attention. A shift in needed care is imperative because older people with ID - like any other older person - will experience physical changes (e.g. sense impairments, declining motor skills, declining ADL-functions), psychological changes (e.g. dementia, depression), social changes (e.g. loss of work, decreasing social network) and spiritual challenges (e.g. death of friends and one’s own death) (Anderson, 1993; Maaskant, et al., 2002).

Diversity in cognitive functioning and aging

Among older persons with intellectual disabilities there is enormous diversity. There are people of various ages, with various etiologies and disabilities. Some have only minor learning disabilities; some will never be able to communicate with words. They all have their own history of socialization, education and residential placements. They all have - more or less - a memory of their past and - also more or less - an idea of their future and how their life will end. Some crave for autonomy and some only feel secure within very strict and structured surroundings. And they age at different rates. They deserve our special care and attention, because as they age they are likely to have fewer resources and will need more help from family, friends and professionals.

It is of immanent importance that persons with ID have basic human rights - the right to life, to health and education, freedom from cruel and degrading treatment, nondiscrimination on the grounds of gender, ethnic background, religious beliefs, class and disability. These rights are enshrined in the United Nations Declaration of Human Rights (United Nations 1948), the subsequent United Nations Declaration on the Rights of Mentally Retarded Persons (United Nations 1971), the Declaration on the Rights of Disabled Persons (United Nations 1975) and the Standard Rules (United Nations 1994). In Europe there is the European Convention on Human Rights (1950) that provides the basis for appeals to the European Court in Strasbourg if there is any reason to believe that any one or more of these rights have been breached.

Inclusion International - together with the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and the World Health Organization (WHO) - have formulated a statement that older people with ID should be included within the fabric of their communities (IASSID/WHO, 1999). This statement recognizes the huge variations among countries which pose a major obstacle to establishing universal principles that address aging and ID. It also recognizes that respect and dignity are the rights of all human beings and pursues four elemental guiding principles: inclusion, full citizenship, self-determination and family support. These principles define good social and public health policies and practices.

Chapter I

Successful aging in the general population and in people with ID

Before going to the realm of people aging with intellectual disabilities it seems useful to take a closer look at what people in the general population do to age successfully.

1.1 Prerequisites for successful aging in the general population

Successful aging - productive aging, healthy aging or aging well - are terms that are meant to supersede former images of old persons as being sick and helpless and in desperate need of care. Successful aging and aging well are concepts that emphasize the idea that people can adapt and maintain satisfying lives as they age, they are about resiliency and adaptability of the aging individual (Johnson, 1995), about exercising choices to create a successful and productive life (Krain, 1995). They also involve a dynamic process that includes the individual in his or her environment, including the historical and cultural context. The concepts are multidimensional, not only encompassing the avoidance of disease and disability, but also the maintenance of a sufficient level of physical and cognitive functioning and preferably a comfortable engagement in social activities. In the literature (Bowling, 1993) it is suggested that successful aging can also be defined as appropriate service use, having access to informal carers, attempting to recover or prevent further decline. In their book “Successful Aging” Baltes and Baltes (1990) present the following key criteria: length of life, biological health, mental health, cognitive efficacy, social competence and productivity, personal control and life satisfaction. Successful aging is not always within the control of the individual, although active involvement in leisure and social activities is one of the best predictors of successful aging, along with good health and financial security (Schaie, 1983). Rowe and Kahn (1997, 1998) give the following three main prerequisites for successful aging:

- avoiding disease and disability,
- the maintenance of a sufficient level of physical and cognitive functioning,
- a continuing engagement with life.

A. Avoiding disease and disability

Research has found (Stunkard, et al., 1990; Heller, et al., 1993; Hong, et al., 1994) that extrinsic environmental factors - what people eat, the amount of exercise they do, whether they smoke or drink alcohol - play an important role in determining the risk for diseases. The findings show that many of the problems that were always thought to be connected with advancing age - like cardiovascular and other chronic diseases - are preventable and modifiable as they are largely due to lifestyle. Additional research (Hazzard & Bierman, 1990; Sticht and Hazzard, 1995) indicates that with advancing age the relative contribution of genetic factors decreases and the impact of non-genetic factors increases.

B. The maintenance of a sufficient level of physical and cognitive functioning

Physical and cognitive vitality is crucial to quality of life and survival into old age. With normal aging some physical and cognitive problems can be found, but there is substantial inter-individual variability. In preventing decline in both, the physical and the cognitive field, the following elements are essential: exercise, living in favorable environmental circumstances, education, a flexible personality style, the maintenance of high levels of perceptual processing speed, self-efficacy and being married to a spouse with high cognitive status (Schaie, 1994; Fillit et al., 2002).

Exercise. Apart from its apparent usefulness for physical fitness, exercise also enhances the central nervous system, particularly the memory function (Neeper, et al., 1995). When cognitive losses do appear among older healthy people they turn out to be reversible by means of training, although younger subjects benefit more than older subjects (Kiegl, Smith & Baltes, 1989). This finding leads to the conclusion that the capacity for positive change persists into old age and appropriate interventions can bring older people back to (or above) some earlier level of functioning.

Living in favorable environmental circumstances, like above-average education, high-complex jobs with low routine, above-average income and intact families (Schaie, 1994).

Education, which is a major protective factor against reductions in cognitive functioning, or more generally stated: a substantial involvement in intellectually stimulating activities such as reading, traveling, attending cultural activities, continuing education activities and participation in clubs (Schaie, 1994).

Individual's self-report of a flexible personality style at mid-life as well as flexible performance on objective measures of motor-cognitive perseveration tasks (Schaie, 1984).

The *maintenance of high levels of perceptual processing speed* into old age (Schaie, 1989): individuals who remain at high levels of perceptual speed are also at advantage with respect to the maintenance of other abilities.

Rating one's self as being satisfied with one's life accomplishments or self-efficacy. This concept was developed by Bandura (1995) and is defined by him as "people's beliefs in their capabilities to organize and execute the courses of action required to deal with prospective situations". The idea of competence becomes even more important when individuals perceive a sense of self-determination: in other words, the more choice a person has in his life, the more he sees himself capable of attaining his goals (Bandura, 1977, 1982). The opposite is also true: if people - especially men - have a low satisfaction with life they will be susceptible to an earlier-than-average decline (Schaie, 1994).

Being married to a spouse with high cognitive status. In their study Gruber and Schaie (1986) found that the lower functioning spouse at the beginning of the marriage tends to maintain or increase his or her level vis a vis the higher functioning spouse.

C. A continuing engagement with life

Maintaining interpersonal relations and staying active are the two main components of a continuing engagement with life. Since Durkheim's classic study on suicide (Durkheim, 1951) it is clear that lack of social ties and isolation are predictors of morbidity and mortality. Being a part of a social network and living an integrated life therefore are significant determinants of longevity, especially for men (House, et al., 1988). But might active engagement with life positively affect cognitive function or vice versa? Recent longitudinal research in the Netherlands on 830 non-demented men and women between the ages 49 to 81 has shown that persons with good cognitive functioning more often engage in leisure-time activities (Bosma et al., 2002). There is a mutual beneficial influence between activity levels and cognitive function that creates a self-reinforcing adverse life-course in middle and old age. There is an overwhelming body of research (Künzel-Schön, 2000) that found that, in general, social support, both emotional (people showing affection and respect to other people) and instrumental (people giving direct assistance to other people, like giving physical help, providing transportation, doing chores, giving money) has relevant positive health effects. On the other hand one must not overestimate these effects: no single type of support is uniformly effective. The effectiveness of the support given depends both on the appropriateness of the supportive acts in relation to the requirements of the situation and the person involved.

The conclusion is that cognitive changes in normal aging are inevitable, but there may well be large individual differences in the ages at which cognitive changes begin. It is known (Christensen, 2001) that on average, older people perform more poorly in areas of memory and cognitive speed (the performance on timed perceptual-motor tasks) than younger people: there is a linear decline starting in early adulthood. Crystallized intelligence “the assumed cumulative end product of information acquired” (Salthouse, 1982) on the other hand increases up to the sixth or seventh decade and may only decrease in late old age. As mentioned above the influence of certain environmental factors on cognitive decline - like lack of good health and disability - is well established, the obvious effect being that one can influence these factors in a positive way. Recent research seeks to dig deeper into the causal relationships that certain brain and cell processes may have on such diverse but related changes in cerebral blood flow and decreased metabolic rate, mitochondrial dysfunction, age related myelin degeneration and, dopaminergic neurotransmitter depletions (Christensen, 2001).

What does the model of the three prerequisites of Rowe and Kahn mean for persons with ID whose well-being is already compromised because of a lifelong disability? Janicki (1999) notices that the authors remain silent in this respect, yet implicit to their theorizing is the idea that the presence of disability may be incompatible to successful aging. This may not be the case however. One can argue that lifelong disability may not be an impediment to successful aging if there are no further significant medical problems to the disability and if the person has developed effective coping strategies and compensatory mechanisms during adulthood and has maintained a lifelong control over his or her life activities (Janicki, 1999). Thus it seems that the notion of successful aging can be applied to persons with ID, especially when viewed from a life course perspective (see Chapter III). Care and service providers should act proactively in order to help adults with ID gain control of their lives, especially in the areas of self-determination and choice-making, as well as encourage their clients to get involved in activities that are both rewarding to themselves and that have positive effects for the communities they live in.

1.2. Aging in people with intellectual disabilities

Before elaborating on the effects of aging within the group of people with ID it is important to be aware of challenges in the research of cognitive changes in older people with ID: the heterogeneity of the group of aging people with ID, the definition of “older people with ID”, certain cohort effects and an increased life expectancy for older people with ID with an accompanied risk of developing chronic and secondary conditions.

First of all it is important to realize that the group of aging people with ID constitutes a highly heterogeneous group of people. Most IQ-tests were never validated on populations of persons with ID and therefore different tests might give different IQ-scores, in the testing situation sensory impairments, emotional problems, a temporarily lessened mental resilience and etiological influences are not always taken into account. This might lead to inaccurate conclusions that a person is aging in a pathological way, while in fact the person being tested was ill at ease or did not understand what the researcher meant. Intellectual Disability is defined and perceived very differently according to culture and context, and therefore statistics relating to exact numbers of persons with ID in the general population must be looked upon with great caution.

Another problem is defining the population of “older people with ID”? There is no fixed cutoff point at which people with ID become old and studies vary considerably with respect to the exact definition (Haveman et al., 1989). Persons with Down syndrome, for instance, appear to be at risk for Alzheimer’s disease as early as thirty years of age (Wisniewski & Merz, 1985). For the sake of clarity in this thesis the term “older people with ID” is used to refer to people over 50 years of chronological age.

Age-specific prevalence rates of ID increase during early childhood - when children enter the school system - but in later life the rates decrease because of an earlier death of persons with profound disabilities (Holland, 2000). Although it is clear from various studies (Janicki et al., 1985; Evenhuis, 1995a,b) that in later life there is a convergence in terms of health and social care needs between person in the general population and persons with ID one has to be careful about drawing certain conclusions too fast in terms of certain cohort effects. Sixty years ago infant mortality would have been higher and neonatal care largely unknown. Persons with severe ID who survived childhood are likely to have been self-selected because of their apparent ability to survive despite the seriousness of their condition. They may have carried this robustness well into adult life and even into old age. Another cohort effect might be the greater chance of being placed into an institutional setting and a lack of formal education.

For almost twenty years there has been a growing interest in persons with ID who are aging (Hogg, Moss & Cooke, 1988; Janicki & Wisniewski, 1985). This is due to the fact that they - apart from people with Down syndrome and people with severe and multiple developmental disabilities, like cerebral palsy and epilepsy - are living longer (Carter & Jancar, 1983; Janicki et al., 1999; Patja et al., 2000) and because of de-institutionalization trends in the western world, have an increased community visibility. Thanks to improved environmental circumstances and a greater medical knowledge the mean age at death for persons with ID was 66 years in 1993, up from 19 years in the 1930s and is now about the same as in the population in general. The rise in life expectancy is even higher in persons with Down syndrome with average age at death rising from 9 years in the 1920s to 56 years in 1993 (Haveman, 2004). With a prolonged life comes the expectation - as in the general population - of an increased prevalence of some age-related health problems, including vision and hearing losses, heart disease, cancer and cerebro-vascular disease. This assumption was confirmed in the study by Janicki et al. (2002) who found for a large cohort of adults with ID aged 40 to 79 years, living in small group residences in New York State, that most adults were in good health. However, with age there was an increase in the frequency of cardiovascular, musculoskeletal and respiratory conditions, and sensory impairments. Due to the confluence of lifelong disability, health care barriers, and adverse lifestyle patterns, older persons with ID are at risk of developing chronic and secondary conditions (Haveman, 2004).

There are three major challenges for older adults with ID to age successfully, namely avoiding disease and disability, maintaining a sufficient level of physical and cognitive functioning and continuing engagement with life.

A. Avoiding disease and disability

Apart from the normal health risks involved in aging, there are complicating factors specifically related to people with developmental disabilities. First, one has to make a distinction between the several levels of intellectual disability. Individuals with profound levels of ID are more likely to have higher mortality rates generally associated with respiratory disease (O’Brien et al., 1991). In addition, a decreased life expectancy has been found in severely impaired immobile persons and those requiring tube feeding (Strauss, & Eyman, 1996). This may help explain the fact that the majority of persons with ID we see surviving into old age have fewer additional handicaps, and typically function in the borderline or mild ranges. Some types of disabilities also have unique aging trends associated with them - as people with Down syndrome aging at a younger age and having a greater prevalence of Alzheimer’s disease (Prasher & Chung, 1996). As persons with ID live longer some diseases like cerebral palsy and polio mellitus have as yet unanticipated late-life consequences like musculoskeletal and organ system disorders. Patterns of medication usage and medication history can also influence physical aging (Adlin, 1993).
Secondly, when people with ID age they are at a greater risk for some secondary health conditions such as lack of exercise, poor mobility, poor eating habits and medication - that may lead to obesity and high cholesterol - than the general population (Adlin, 1993; Rimmer, et al., 1995), and often lack knowledge about the importance of healthy behaviors - such as good nutrition and exercise. They also often have only limited decision-making power in the choice of food (Heller, Factor, Sterns & Sutton, 1996). Information on the importance of healthy behaviors as people age - as part of a Later Life Planning course, for instance - is a good avenue for educating aging adults with ID about the importance of making healthier choices and engaging in healthier behaviors (see Chapters V and VI).

Another explanation for the great variance in health status lies in the circumstances in which people live. Apart from the apparent - medical - causes for a greater risk for disease and disability, most people with developmental disabilities - especially those living independently in the community - have poor health maintenance practices, and almost all have difficulty communicating with health care providers (Edgerton et al., 1994; Lennox et al., 1997; Lennox & Kerr, 1997; Cook & Lennox, 2000) and they are often unable to indicate the existence or location of the pain felt by them (Lennox et al., 1997). These difficulties are partly due to communication impairments and cognitive deficits, but people with mental retardation also tend to not self-report symptoms, besides, many people with ID feel uncomfortable because they are unfamiliar with the various medical screening procedures such as blood test and visual or auditory examination (Barr et al., 1999). Yet another reason for the mentioned difficulties might lie in the fact that care providers often are unfamiliar with people's health histories due to frequent residential moves of the person involved or staff turnover and family members may be unavailable or uninvolved and therefore an adequate anamnesis is difficult or impossible to make. Although some research (Rimmer, et al., 1995) indicates that people living in residential facilities in the community and with their relatives usually have adequate health care provided for them, some other studies show unrecognized and therefore untreated mental and physical disorders and disabilities, such as visual disorders (Beange et al., 1995; Barr et al., 1999), epilepsy (Beange et al., 1995; Ryan & Sunada, 1997) hypertension and hypothyroidism (Barr et al., 1999). This tendency to underreport and therefore to undertreat persons with ID by the health system is called detection bias (Haveman, 2004). Another reason for insufficient health care for people with ID is the different etiology of certain health care problems, which makes a different treatment necessary (Evenhuis, 2001). On the basis of comparative research among persons with ID Jansen et al. (2004) conclude that this group shows higher prevalence rates for epilepsy, diseases of the skin, sensory loss and a (increased) risk of fractures, these health problems being specific for persons with ID in general, but particularly for persons with ID living in the community.

B. The maintenance of a sufficient level of physical and cognitive functioning

In their review article (1997) and in their book (1998) Rowe and Kahn give the following predictors of decline of physical performance:

- a low socio-economic status: being older and having an income of less than $10.000 a year has a negative influence on successful aging. It is clear that older people with ID likely earn less than $ 10.000 a year and generally live in poverty;
- a higher body mass index (obesity), high blood pressure and a high level of cholesterol are detrimental to maintaining good health into old age: on all these measures people with ID are at higher risk;
- lower initial cognitive performance: it is quite obvious that people with ID start at a low level from the very beginning of their lives.

People with ID can age gracefully too as many of the predictors of risk and of functional and activity levels are potentially modifiable, either by themselves or by other individuals or by changes in the immediate environments. Perhaps for persons with ID the above-mentioned concept of “aging well” (Johnson, 1995) is more appropriate than the concept of “successful aging”. “Aging well” does not necessarily equate success with the lack of disability, but emphasizes the importance of people living well to the best of their abilities. “Aging well” also stresses the primacy of the environment and individualized supports in influencing favorable outcomes for older adults like:

- maintaining good physical and mental health and functioning as independent as possible;
- an active engagement with life; which means maintaining friendships and participation in community life.

Aging is a life-long process and how well a person ages very much depends on events that occurred at younger ages: “aging well” is all about making choices that create a successful and productive life (Krain, 1995).

Expanding on Bandura’s (1995) concept of self-efficacy - another essential element in maintaining a sufficient level of physical and cognitive functioning into old age - Wehmeyer (1992) notes that self-determination specifically refers to attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s action free from undue external influence or interference. As previously discussed (Heller, Factor, Sterns & Sutton, 1996), older adults with ID often are not provided with opportunities to participate in planning and decision-making about their later-life activities. Here again the Later Life Planning course can make a difference especially regarding promoting an active, healthy lifestyle throughout the lifespan.

C. A continuing engagement with life

According to Janicki (1992) when older persons with ID are faced with the option of retirement, many are not aware of the consequences of their retirement or of the alternatives. He reported that older persons with ID find that the loss or change of friends when moving to a new program can pose a significant barrier and that many seniors are reluctant to retire to senior programs because of fear of losing their workshop or job income and close network of friends made in the workplace.
Heller et al. (1996) noted that lack of leisure activities can impede healthy behaviors among adults with developmental disabilities. Compared to their peers who do not have disabilities, older adults with ID are less likely to attend movies (42% vs. 71%), live music performances (24% vs. 49%), or sports events (29% vs. 56%) (Harris et al., 1994).
This lack of involvement or lack of opportunity of involvement is disturbing in light of the positive effects of a continuing engagement with life on successful aging, namely promoting social interaction and community integration (Liberman, et al., 1984), improving physical and mental health and making significant contributions to self determination (Iso-Ahola & Mannell, 1984), and on friendships and social supports bolstering self-confidence and self-esteem (Bullock & Luken, 1994).

Hence, the need is ever more evident to reinforce self-determination and train persons with ID on choice making as well as to learn them how to keep good health, to actively plan their leisure and recreational activities, to maintain friendships and to keep a continuing engagement with life. The curriculum “Later Life Planning for Adults with Mental Retardation” (Sutton et al., 1994) that will be discussed in Chapter III provides ample opportunity for older persons with ID to obtain the prerequisites to help them forward on the road to aging well.

Chapter II

Health risks for people with intellectual disabilities

2.1 Health changes

Before turning to the physical changes and illnesses people with ID might encounter it is important to state that over the last 40 years most research into the health status of people with ID was done in institutions. It is possible that the results of these studies are not representative for persons living in the community and who never were institutionalized (van Berkum & Haveman, 1995). The “old” population may have suffered from a cohort or period effect (Haveman & Stöppler, 2004) given the fact that families and local authorities often did institutionalize persons with ID.

Some of the more obvious - and non-threatening - physical changes in older people are the graying of the hair and the wrinkles in the face. More serious changes are a decline of muscle power, a drop in the heart rhythm, an increasing inflexibility of the joints, and a decreasing of lung capacity and lung volume. These are not illnesses, but are age-related declines to which one must adapt oneself. The following are illnesses often seen in aging people (Künzel-Schön, 2000):

- cardiovascular diseases (for instance, coronary illnesses, arteriosclerosis, high blood pressure);
- musculoskeletal diseases (arthritis, osteoporosis);
- lung diseases;
- metabolic diseases (diabetes mellitus);
- diseases of the central nervous system (Parkinson, glaucoma);
- cancers (intestinal, prostate).

Whether an “inconvenience” is considered to be an illness depends upon any number of organical, physical and circumstantial factors, but also on what the person involved perceives as an illness (Hartmann, 1989): the older the person, the weaker the connection between an objectively found illness and the - subjective - sense of illness in that person. The most important thing however is that not all elderly persons will fall ill; it is a very individual process. The same can be said about dementia: more older people have dementia, but it does not apply to every person over 60 years of age.

Genetic make-up and lifestyle are the major determinants of health risks. A well-known high risk for adults with ID is malnutrition. Age-related changes, chronic diseases, cognitive and functional decline, feeding problems, multiple concurrent medications and their nutritional implications, and syndrome specific morbidity and co-morbidities make them a nutritionally vulnerable group.

Now more and more people with ID are living in the community, they have more options for (unhealthy) choices in food, resulting in a higher prevalence of secondary complications such as overweight and obesity, coronary heart disease and type 2 diabetes (Rimmer, 2000). Obesity is also a well-known health risk for people with Down syndrome and Prader-Willi.

Physical exercise is a protective factor in terms of healthy aging. However, Pitetti et al. (1993) found that, even when mobile, adults with ID are often prevented from exercising because of staffing, financial or transport barriers. The resulting inactivity is a risk for cardiovascular and other diseases and prevents a general feeling of well-being. There is evidence (Beange, 2002) that exercise has a positive influence on mental health, including reduction of hostility, anger and depression.

2.2 Health problems

Studies have found a higher prevalence of health problems in the older population with ID, whether people live in institutions or dwell in the community (Maaskant & Haveman, 1990; van Schrojenstein Lantman-de Valk et al., 1997) than in the general population.

Table 2.1 Prevalence (%) of health problems for persons with and without ID registered with Dutch GPs.

Health problem	with ID	without ID
multiple congenital anomaly	5.9	0.4
epilepsy	11.0	0.8
disability/impairment musculoskeletal	6.0	0.5
strabismus	5.3	1.1
premature/immature live-born infant	4.1	0.9
other disorders CNS	4.4	1.1
all perinatal morbidity	5.3	1.5
deafness	6.3	2.3
fracture lower leg	5.0	1.9
obesity QI> 30	8.8	3.5
congenital anomalies musculoskeletal	3.1	1.3
acne	4.1	1.6
contact dermatitis or other eczema	5.7	2.9
hemorrhoids	3.5	1.8

From: Van Schrojenstein Lantman-de Valk et al. (1997, p. 90)

As can be deducted from Table 1 persons with mild and severe ID (N=318) have 2.2 and 2.7 respectively, more health problems than persons without ID (N=48,443). The most common illnesses among persons with ID compared to persons without ID are epilepsy, musculoskeletal disabilities (e.g. cerebral palsy), strabismus, deafness, fractures obesity, acne, eczema and hemorrhoids. Beange et al. (1995) report a mean of 5.4 medical problems per patient. A lack of early diagnosis and treatment of these conditions leads to more social deprivation and reduction of quality of life.

Evenhuis (1997) concludes that people with ID tend to tolerate symptoms or express them atypically as irritability, inactivity, loss of appetite and sleep problems, particularly for conditions such as visual impairments, hearing loss and chest pain, rather then report them. One of the detrimental effects of de-institutionalization might be that when persons with ID are relocated from institutions to the community, they lose access to (generic) health care services (Kastner et al., 1994), a fact that could still be observed ten years later (Beange, 2002). Among the impediments are problems with mobility, the inaccessibility of the services - both at a physical and emotional level - and communication problems of the clients themselves (Day &

Jancar, 1994). Nevertheless, conditions can be diagnosed as accurately as in the general population as long as health professionals use routine diagnostic screening methods, use their knowledge of risk factors and atypical presentations and take into account carer observations.
The health problems of the younger cohorts are quite dissimilar. In the younger groups the prevalence of epilepsy and cerebral palsy is higher than in the old, while the youngest age groups are more likely to have cardiac disorders (Van Schrojenstein Lantman-de Valk et al., 2000). Because of this multi-morbidity, persons with severe and profound ID and people with Down syndrome die earlier (Haveman et al., 1989).

The most prominent health problem of people with ID are *sensory impairments*. Evenhuis et al. (2001) found a much higher prevalence of hearing and vision impairments in 672 Dutch institutionalized people as compared with the general population. In persons with severe and profound ID of all ages, sensory impairments were more frequent than in persons with mild or moderate ID (Van Schrojenstein Lantman-de Valk et al., 1994). Both vision and hearing functions seem to deteriorate as people grow older (Van Schrojenstein Lantman-de Valk et al., 2000; Warburg, 2001).

Epilepsy is also very much related to intellectual disability (Van Schrojenstein Lantman-de Valk et al., 2000), not only as a possible cause but also as a deteriorating factor. Coulter (1993) finds a prevalence rate between 20% and 30% of the population. Epilepsy in itself can cause sudden death, but also leads to higher morbidity because of fractures, soft tissue injury and hospital admissions.

Thyroid disease is known to be a cause as well as a complication of intellectual disability, especially in people with Down's syndrome. Hyperthyroidism may cause behavioral problems and must therefore be checked on a regular basis.

Constipation has been a well-known phenomenon in institutions. Recently a Dutch survey found that 69% of the 215 persons studied had problems in this area (Bohmer et al., 2001). In this study obstipation typically occurred in combination with cerebral palsy, medication usage, food refusal and an intelligence quotient below 35.

Obesity is also a very well known phenomenon in people with ID, especially in people with an IQ over 30 (Van Schrojenstein Lantman-de Valk et al., 2000). A possible explanation for this finding might be that persons with mild and moderate ID can move around more easily to get some extra food, while people with severe intellectual handicaps are more bed-ridden or in wheelchairs.

Genetic diseases are a major cause of ID. Raynham et al. (1996) found that in 40-50% of the persons with ID there was a genetic etiology. They estimated that for 15-20% the ID was due to environmental factors and for 35-45% the cause was unknown, but with further research part of the latter percentage might also be attributable to genetic diseases.

Secondary effects. In a Dutch survey of 1265 people living in either institutions or group homes Van Schrojenstein Lantman-de Valk et al. (1995) found that 57% of the persons used one or more *medications*. The number of drugs taken was significantly related to increased age and level of intellectual disability. The use of antipsychotics, laxatives and cardiovascular medication was dominant in older persons, whereas younger persons more often used anticonvulsants. The greater use of antipsychotics, anticonvulsants, laxatives, antacids, psychoactive and gastrointestinal medication was significantly related to the level of ID.

2.3 Mental health problems

The aging process itself can have serious effects on the mental health status of persons with ID. Changes in physical status, like losses of vision and hearing, use of medication, reduction in mobility as well as behavioral challenges in adapting to new living arrangements can result in mental health problems. Ill health in itself may also be a cause for behavioral problems (Davidson, 2003). A third cause of mental health problems is emotional reactions related to adverse life events, such as losses of family, friends and peers (see Chapter VI).

Over the last decades there has been an increasing interest in finding new ways to treat persons with ID and chronic mental health problems (Dosen, 1995). The pedagogical perspective that can often be found in the care for persons with ID is not sufficient to address mental health problems. Psychotropic medication, and psychotherapy - on an individual, group or system level - can have positive effects (Dosen, 1990). It is, however, often necessary to adapt the traditional psychotherapeutic techniques to the communicational level and attention span of the client with ID.

In order to obtain the best conditions for a good quality of life for persons with ID and chronic mental health problems there should be a close working relationship between the two service networks of mental health and ID, especially when these services are apart as they are in the Netherlands since the 1970’s (Derks et al., 1995; van Laake et al., 1995; van Laake, 1999) or through specialized services as is the case in the UK (Day, 1995). A look from only the medical perspective - psychiatry - or from only the educational/environmental perspective - pedagogy and psychology - offers a far too narrow scope.

Bandura (1977, 1982, 1995) pointed to the importance of perceiving oneself as self-efficient and self-competent. The idea of self-competence is especially important for persons with ID: if they can make choices they will have more influence on the world they live in. Wehmeyer & Metzler (1995) however, have indicated that persons with ID seldom have opportunities for daily choice-making.
With the overwhelmingly positive effects of self determination and choice-making in mind (see Chapter I), the curriculum “Person Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994), that will be discussed in Chapter IV, came as a great help: for the first time there was an opportunity to teach persons with ID how to make choices in several domains of their lives and henceforth influence the world they live in. But first key philosophical concepts in providing care for aging persons with ID will be discussed.

Chapter III

Key concepts in aging in people with intellectual disabilities

The last thirty years fundamental changes in the philosophy of care and clinical advancements have created a whole new set of ideas along which services for (older) people with ID are organized. The most important change includes the movement towards integration, participation and choice. In Western Europe and in the US most institutions for people with ID have completed their process of de-institutionalization but retain some long-stay beds for persons who have enduring mental illness or challenging behavior as well. Services for persons with ID may either be centered around a residential provision, with some outreach work or are community based (Bouras, et al., 1995).

The key concepts in aging in people with ID that will be discussed in this chapter are:
- life cycle and family caregiver considerations,
- person-centered planning,
- the normalization principle,
- self determination and choice-making,
- empowerment.

3.1 Life cycle and family caregiver considerations

For many families the presence of a person with ID means lifelong care and involvement. The aging of caregivers and the longer life expectancy of adults with ID increase the period of parental caregiving and the likelihood that adults with disabilities will survive well into old age and outlive their parents. Though the percentage of people with ID living at home declines with advancing age, a small number of them still lives “at home” with parents who themselves may be over 60, sometimes in their 90s. In comparison with the general population parents who have provided long-term care for their disabled child tend to have reduced maternal employment, more family-work strain, and alterations in lifestyles combined with a variety of stresses that increase the burden of care, some of which are specifically linked to the aging of the caregiver - mostly the mother - and her adult child (Seltzer et al., 2001). It is also possible that this “child” in turn becomes a major resource for the mother. Therefore one must always look very carefully into the cultural differences in attitudes to family care and what motivates it. In some ethnic groups in developed countries - and in some developing countries - continued family caregiving rather than sending the person away in the wider community remains the norm (Seltzer, et al., 2001). Because so many of the adults with ID living at home or in residential settings are aging, their parents may no longer be living or capable of being involved in their relatives’ lives. Thus, other family members, such as siblings and other extended family members, may need to be encouraged to become involved in the lives of their relatives with disabilities (Krauss et al., 1996).
On the other side of the spectrum there is an increasing role of grandparent caregivers because parents are absent, addicted or otherwise unable to carry out their parental duties. Over time some negative consequences to prolonged caregiving may emerge as the interests of the caregiver and the person cared for

start to diverge: both may have very different views on what should happen in the future. Person centered planning may be the context in which the interests of older persons with ID and their caregivers can be realized.

3.2 Person-Centered Planning

According to the AAMR definition the term Person-Centered Planning (PCP) refers to a whole body of ways and means "to organizing and guiding individual and community change in collaboration with individuals with disabilities, their families, and their friends. PCP requires important investments in order to build both personal and community support." (AAMR Fact Sheet: Person-Centered Planning, 2001)

The concept of person-centered planning started in the mid-1980s as a conscious search for new ways through which to understand the experience of people with ID and to work together with them, their families, friends and other caretakers to change hitherto common patterns of their lives - including segregation and having to live together with other people with disabilities, devaluing stereotypes, inappropriately low expectations, and denial of opportunity - into respect for the dignity and completeness of the person (Mount et al., 1991; Mount, 1992a; 1992b; O'Brien, 1987; O'Brien et al., 1992; 1997). Instead of focusing on disabilities, person-centered planning emphasizes the capacities of the person, looks for what that person wants with his or her life and investigates the supports he or she can get from family and friends, the community and professional workers in order to attain his or her goal. Therefore it is important to promote a change in services in such a way that services become more responsive to the individual needs and interests of persons with ID and to support these persons in their search for effective ways to deal with difficult barriers and conflicting demands.

3.3 The Normalization Principle

Person-centered planning originates in the normalization principle that was first described by Nirje (1969, 1972) and Bank-Mikkelson (1980) and was further developed in North America by Wolfensberger (1972). Normalization evolved as a human rights-based, critical reaction to large institutions where - since the 19th century - persons with ID and psychiatric patients lived very deprived and abnormal lives compared with the lives of ordinary people. Nirje wrote about the importance of people with ID being given access to the "normal rhythms of life" and a separation of life functions in stark contrast to the way people lived and worked in institutional settings (Nirje, 1985). In his book "Asylums" Goffman (1968) describes the essential characteristics of institutional life: almost all functions are carried out in one place, perhaps even in one room or one ward, whereas in normal society people live in one place, work in another, be educated somewhere else and spend their leisure time in a variety of places. In his later work Nirje (1992) expands his ideas on the right of persons with ID to normal rhythms of the day and the week to their rights to a normal rhythm of the year; to normal developmental experiences of the life cycle; to having a range of choices, wishes and desires respected and considered; to living in a world made up of two sexes; to the right to normal economic standards and to living in normal housing in a normal neighborhood. In short: making available to persons with ID conditions of every day life, which are as close as possible to the norms, and patterns of the mainstream of society (Nirje, 1969). This change away from hospital care to a social care model has - as an example - resulted in England in a closing down of long-stay institutions with a reduction from 70,000 residents in 1970 to 3,000 in 1999 (Hollins, 2000). In the Netherlands, at the end of 1945 (with 9 million inhabitants), 22,700 patients remained in 37 general mental hospitals; in 1955 (with 12 million inhabitants) the Dutch mental hospitals had, with 28,000, reached a maximum number of institutionalized patients. In the years 1955-1975 there was a gradual decrease with 17%; which means that at the end of 1975 there 23,240 beds. This process, however, was slow compared to the deinstitutionalization process in the UK, Italy and the US. In the US, for instance, in the same period the figures for state and mental hospitals showed a decrease of 66% in inpatients (Haveman, 1986).

Recently the Dutch Department of VWS (Health, Social Affairs, and Sports) (Brancherapport GGZ-MZ 1998-2001) presented data showing that at the end of the year 2001 there were 23,565 beds in general mental hospitals, 1,516 in mental health units in general hospitals and 459 in mental health units in academic hospitals, a total of 25,540 beds on a population of 16 million people. This figure does not include the 6,124 persons with chronic mental health problems living in Regional Institutions for Sheltered Living

So notwithstanding all efforts the actual number of beds in Dutch mental hospital did not decrease since 1977: it actually kept growing.

In the nineteen-eighties Wolfensberger (Wolfensberger and Thomas, 1980) developed the normalization principle into the Social Role Valorization (SRV) theory which emphases the use of culturally valued means to enable, establish and/or maintain valued social roles for persons whereby “devalued” persons become “valued” members of society. The first strategy to obtain this goal is to reduce stigma and the second is to change perceptions of the general population through the re-valuing of “devalued” people. Development of service systems for persons with ID that have to focus on the enhancement of a “devalued” person’s social image and competencies.

In 1985 Perrin and Nirje argued that SRV with its emphasis on conformity and the acquisition of culturally valued roles sharply contrasts with normalization as they see it: with an emphasis on the integrity of the person, the right to make choices and the right to self-determination, rights that should be observed even if society does not like the route the person with ID chooses to go.

Already in his 1969 paper Nirje argues that when work is no longer possible, like in the normal older population, older persons with ID should be able to live as close to the place where they have spent their adult period of life, in case they cannot remain in that very place; familiar settings and old acquaintances will give their lives content and leaning. An opinion confirmed by a Dutch study: Staring & ten Horn (1998) found that just like other older people living in the community older persons with ID preferably have contacts within their own social circle that not only consists of family and professional caregivers, but also with a wide array of other friends, acquaintances and other people they know from within their “own world”.

Person-centered planning sessions bring together the most important people in the life of a focus person, including that person, family members, friends and others who spend the most time with the person involved. Participation in the sessions is voluntary and usually entails a long-term commitment with the aim being to help plan a better lifestyle based on the person’s interests, talents, and preferences (Mount, 1992a; 1992b). Although the process identifies and builds on the person's strengths, capacities, and preferences, neither professional authority nor technical language is prominent. Meetings are organized and conducted by a skilled facilitator, who guides the group with several core principles or values, which include community inclusion, personal autonomy, making a social contribution, and building relationships (Mount et al., 1990; Holburn et al. (2000). The initial meetings are devoted to mapping out what is known about the person. The maps highlight the person's history, routines, relationships, community involvement, preferences, dislikes, available choices and other pertinent information. Common themes emerge from the mapping, which guide the group in crafting a vision of a desirable future lifestyle. The group brainstorms strategies for achieving these lifestyle changes and acknowledges the obstacles to their achievement, and members volunteer for specific tasks. Easy-to-resolve matters are addressed first. Resolution of more significant issues usually requires negotiation with people outside the planning team, at which point system obstacles are often encountered. At follow-along meetings, the group reviews accomplishments, discusses unresolved issues, and develops new action steps to keep the process moving forward. New issues may emerge as the person's life begins to change. It is obvious that this type of planning is focused on the capacities and strengths of individuals with disabilities and their support network, whereas the more traditional planning process, which was often focused on deficits (Abery et al., 1998).

The importance of the process of person-centered planning is underpinned by the recent research done by Mahon and Goatcher (1999). They evaluated a later-life planning program that focused on promoting leisure activities in retirement among older adults with ID finding that compared to a control group, participants in the program experienced a considerable increase in their life satisfaction, which in turn leads to an enhanced quality of life.

3.4 Self-Determination and Choice-Making

Personal future planning is closely linked to self-determination and choice-making, which refers to the importance of people taking control of their own lives and making the decisions that affect them. As a result of the broad impact of the normalization principle and the independent living movement - which emerged almost in parallel with it - many persons with ID left the old institutions and came to live in small facilities in the community where there are more opportunities to make choices (Stancliffe, 1997), a more home-like atmosphere, and more opportunities for families and friends to get involved in the residents' lives (Conroy, 1996; Wehmeyer et al., 1999a; 1999b; Emerson et al., 2000). It may be that it is not the type or size of the residential setting per se that accounts for the greater residents' well-being, but that their well-being is enhanced by the specific aspects of smaller, community-based residences, the opportunity for autonomy and the physical attractiveness of the place.

Heller et al. (1999) found that greater opportunities for persons with ID to be involved in decision-making were associated with greater adaptive behavior, community integration and health. Living in a more attractive, home-like physical environment helps a person with ID to feel better over time: an environment that is attractive, clean and well maintained tells people with ID that they are viewed positively and as persons of dignity. When a person with ID values him- or herself more there also could be a greater family involvement and families may be more likely to encourage their relatives to actively participate in community life.

Most theory, research, and intervention involving choice-making and self-determination in persons with ID have focused on self-determination skills, such as goal-setting, decision-making, problem-solving, self regulation and personal advocacy (Tymchuk, 1985; Field & Hoffman, 1994; Sutton et al., 1994; Wehmeyer & Metzler, 1995) Many of these skills require sophisticated cognitive and verbal abilities far beyond the reach of most persons with severe or profound ID, though with the help of a very supportive environment a person with severe ID and multiple disabilities can be able to exercise greater personal control, even if that individual has not yet been able to exercise choice independently. Most persons with severe and profound ID are likely to only have control over the more basic aspects of their lives, e.g. choice over every day activities like choosing one's clothes or bedtime (Stancliffe & Abery, 1997). Individuals with profound ID had lower baseline choice scores, but benefited equally from deinstitutionalization (or suffered equally from continued institutionalization) as participants with less severe ID. Everyday decisions that did not directly involve other people - such as when to go to bed or get up, or what clothes to wear - appear to have been more available and more strongly affected by deinstitutionalization. Decisions involving others, such as scheduling when to eat or go out with family or friends, were very rarely available and seemingly less affected by the move into the community. People that moved into society had more choices in bedtime, leisure activities and food, and the purchase of personal items than persons that stayed behind. Despite all good intentions there were quite a number of persons living in community based settings that had no choices at all (Stancliffe & Abery, 1997). Even now, with more people living in the community, many choices in daily routines, including work and leisure activities, are still determined by service providers (Jenkinson, 1999). There will always remain a tension between what a person with ID really wants and what parents and caregivers perceive of what is "good" for them. This challenge is highlighted by Baggerman et al. (1990) in their article with the compelling title: "Balancing the right to habilitation with the right to personal liberties: The right of people with developmental disabilities to eat too many doughnuts and take a nap".

Lack of availability of resources or options as well as perceived personal and cognitive factors emanating from the person's impairment and past history will probably continue to limit opportunities for decisions that have implications beyond day-to-day choices (Jenkinson et al., 1992). An American consumer survey of self-determination among people with ID (Wehmeyer and Metzler, 1995) confirmed that the opportunity to participate in major decisions - that is decisions affecting their lives - is related to the importance of that decision. Choosing the shape, size and place of one's residence is one of the major and most decisive decisions that any adult must face, but the (residential) placement of a person with ID in many instances is primarily decided by those legally responsible for that person, which proves that persons with ID are very unlikely to have control over important choices and decisions that deeply affect their quality of life. Research findings show nonetheless that an increase in the capacity of persons with disabilities to make choices regarding their own lives will raise their level of independence, community integration, and quality of life (Heller et al., 1999). As was the case with the doughnuts and the naps, here again there may be conflicts between protection and safety issues on the one hand and autonomy and risk on the other. There may also be a lack of flexibility and/or restrictions on options available to people who are dependent on support services, as well as poor social and economic circumstances.

The opposite of self determination is learned helplessness; a condition that develops when people lose or are denied control over their own lives and become dependent upon others (Seligman, 1975), a condition which has been observed to occur in persons with ID as well (Weisz, 1982). Insufficient opportunities for decision-making and problem solving, and the absence of appropriate learning experiences to acquire competent behavior, contribute to this condition in people with ID who live at home as well as those who reside in institutions (Floor & Rosen, 1975). Competent decision-making will not occur simply by making available relevant information about options and their consequences. Individuals who have had experiences leading to learned helplessness may require a lengthy period of supported practice in making decisions in order to gain greater confidence and feelings of control. At the same time, attention must be given to avoiding an overload of information when a decision has to be made.

Most importantly, there is ample evidence to sustain the premise that persons with ID can learn to choose and to make personal, independent decisions (Mahon, 1992; Wehmeyer et al., 1999b; Stancliffe et al., 2000). Therefore, the means and opportunities to enable people with mental retardation to make decisions for themselves should be further developed and significant efforts should be made both to involve them in all decisions and to minimize the number of matters over which others exercise control. This will eventually contribute to a greater quality of life of the person involved (Schalock, 1996). People who are highly self-determined experience a higher quality of life (Convoy, 2001).

Sparked primarily by the self-advocacy efforts within the population with disabilities (Kennedy, 1993; Heller et al., 2000) increasing attention is being paid by educators and service providers to promoting the self-determination of persons with ID through changes in policy and program development. These programs have led to increased initiation of leisure activities, enhanced feelings of control, and greater independence among members of this population (Gaudet & Datillo, 1994; Searlle et al., 1995). But one has also to be cautious: when looking at people with ID one should be aware that they do indeed have a handicap - they are impaired in their mental competency - may not be able to exercise self-determination and choice to the full. Without sufficient support and guidance they may jeopardize their safety and health. Many adults with severe ID need to have competent advocates at their side who are willing and able to make wise decisions with them or on their behalf, even if these do not always please a person of limited, disturbed, or diminished capabilities.

3.5 Empowerment

The word “empower”, according to the Oxford Dictionary of the English Language has two related meanings: 1) to give authority or power to; to authorize; and 2) to give strength and confidence to somebody. There is built into the term a quality of relationship between a person and the outside world, being his or her community, working place or place of residence: it is important to know what or who one has authority over.

Rappaport, one of the founding fathers of the concept describes the word as follows (1987, pg. 121): “Empowerment … suggests both individual determination over one’s own life and democratic participation in the life of one’s community, often through mediating structures such as schools, neighborhoods, churches, and other voluntary organizations.”

To increase one’s empowerment a person needs to have access and control over needed resources, be able to make decisions and solve problems that appear during this endeavor and work effectively with others in such a way that he or she can indeed effectively use these resources. The power idiom and thinking - as expressed in empowerment - began to infiltrate from the political arena into the human service and advocacy culture in the 1970s and did not become commonplace there until the late 1980s. Once the empowerment construct and idiom became popular, it became a “container concept” and was applied to almost anything (Wolfensberger, 2002).

All the concepts described above - normalization, integration, self-determination, choice making and person centered planning - come together in the two concepts on which the “Person-Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994) is built: the ecological perspective on empowerment and the lifespan developmental perspective.

The “ecological perspective on empowerment” suggests one has to take the environment into account, as well as the relationships between people, policy, programs and professionals over time. The ecological approach provides a much broader range of contextual understanding than is typically the case in the person-centered approach (Trickett, 1984).
The broader ecological perspective on empowerment also assumes that a person is competent or has the capacity to become competent. Poor functioning is seen as due to the failure of the social system to create opportunities for competency. People need to be empowered in order to be able to deal more effectively with their environment, with the major consequences of an increased well-being and the enhancement of problem-solving abilities.

The concept of “lifespan developmental perspective” assumes that persons are modifiable and open to changes at all ages, implying that also at an older age people can learn new skills and behaviors.

3.6. Concluding remarks

The concepts discussed in this chapter - person-centered planning, normalization, empowerment, self-determination and choice-making - are the cornerstones on which the curriculum “Later Life Planning for Adults with Mental Retardation” is built. Starting from the normalization principle that all persons with ID should enjoy those conditions of every day life that are as close as possible to the norms and patterns of the mainstream of society (Nirje, 1969) the curriculum is meant to empower older persons with ID to gain control of their lives, by exercising self-determination and choice-making. As was shown in Chapter I these two concepts are key to helping promote successful aging in later life. Successful aging is the combination of avoiding disease and debilitation (Chapter II) and maintaining health and physical capacities, providing a stimulating environment and ensuring that social networks and community engagement are utilized to the fullest extent possible. The curriculum “Later Life Planning” aims to empower older persons with ID; it teaches them how to make choices and their rights and responsibilities, the importance of eating healthy food and doing exercise, options for leisure time, how to make and maintain friends, living arrangements and how to spend time after work. Through a person-centered planning process the curriculum aims to build these options and choices into the lifestyles of the older students and thereby promotes successful aging.

The next chapter will be devoted to the description of the training “Person-Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994).

Chapter IV

The Curriculum “Later Life Planning for Adults with Mental Retardation”

Introduction

For persons with ID many of life options may not be available. Apart from finding a partner for life, one of the other most difficult things to obtain is a regular job. Ashman et al., (1995) investigated the employment and retirement status of persons with ID aged over 55, living in two Australian states. Many of the interviewees wanted to work or to have worked, but the majority had never had had that opportunity.
For most persons aging in the population at large one of the clearest boundaries to cross when getting older is retirement from work to a life where there is plenty of time for hobbies and other relaxing activities. Many persons with ID do not know or experience this transition, which - together with other differences in the overall structure of their lives - often leads to a failure to recognize and plan adequately for a life without work obligations and to provide for the necessary changes in lifestyle when required.

The course “Person-Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994) is designed to prepare older persons with ID for these lifestyle changes: they learn how to make (healthy) choices, how to spend their leisure time, when and how to stop working - even if “working” means visiting a day activity center - and how to make friends. The course builds on two multidisciplinary complementary orientations: life span developmental perspective (Baltes & Danish, 1980) and the ecological perspective on empowerment (Rappaport, 1987) that are both discussed in Chapter III. The first principle means that persons - also persons with ID - can learn well into old age and have the right to make choices concerning their own life; the latter means that although individual possibilities and choices may vary, a person should get support and help from his or her environment to be able to attain the goals that person has set. Therefore it is important not only to teach choice-making skills and aging concepts, but also to create opportunities to practice and demonstrate (newly) learned competences.
In addition to a focus on developing skills and knowledge, the later-life planning training program uses an approach to working with adults with ID that is based on person-centered planning. Person-centered planning is “a set of values and strategies that can be used to assist an individual in creating a vision for the future and a plan for working with others toward realizing that vision (Abery & McBride, 1998, p.3). Person-centered planning involves collaboration with people who know the individual with a disability well and who are willing to support that individual in achieving his or her goals. The focus is on the strengths and capacities of both the individual with a disability and his or her support network rather than on possible existing deficits.

The major goals of the Later Life curriculum can be worded as follows:
- To increase participant’s knowledge of later-life options;

- To facilitate greater individual choices and participation in decisions affecting his or her life;
- To facilitate realistic goal setting by the participant;
- To maintain and/or increase individual's wellness behaviors;
- To increase individual's participation in leisure and recreational activities, including participation in community-based activities;
- To increase individual life satisfaction;
- To change staff behavior to facilitate greater encouragement of personal choice making among older adults with ID.

Increasing the capacity of individuals with disabilities to make decisions regarding their own lives is based on the premise that greater autonomy will increase the level of independence, community integration and quality of life (Wehmeyer & Metzler, 1995).

One of the main principles in adult education is to start from what participants already know (Knowles, 1990). The trainer has to seize every opportunity within the boundaries of the curriculum to assist participants to learn from each other's experiences. Therefore he or she has to promote and role model participants' communicative skills and other social behaviors. Participants are encouraged to tell about their experiences, to listen to each other's stories, to tell what they think, to exchange opinions and work together. Further important aspects of the training are creating the feeling that participants belong together as a group and share a common goal. The trainer also promotes friendships between participants.

4.1 "Person-Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation"

The training material consists of an instructor's script and guide, a student's notebook, graphics, a choice maker chart and assignment and reminder envelopes. The curriculum "Person-Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation" (Sutton et al., 1994) includes 17 lessons and two field trips.

The seventeen lessons are:
Lesson 1 Introduction of the Curriculum Content and Getting Acquainted
Lesson 2 Choice Making
Lesson 3 Rights and Responsibilities
Lesson 4 Making Healthy Choices as We Grow Older
Lesson 5 Exercise
Lesson 6 Exercise and Other Healthy Choices (continued)
Lesson 7 Free-Time Activities
Lesson 8 Free-Time Activities (continued)
Lesson 9 Work / Retirement: Possible Schedule Changes in Later Life
Lesson 10 Work/Retirement: Possible Schedule Changes in Later Life (continued)
Lesson 11 Friendships and Support Networks
Lesson 12 Making Friends in the Community
Lesson 13 Volunteering
Lesson 14 Places We Live
Lesson 15 Improving Life Where You Live It
Lesson 16 The ISP Meeting and Goal Setting

Lesson 17 From Goals to Action Plans: A session for class members, support persons, family members and associated staff.

In the training modules participants are encouraged to express choices, learn about realities affecting their choices and learn how to advocate for their choices.

Normally, in a curriculum on Later Life Planning there would also be a lesson on money and finances. In this curriculum for older persons with ID there is no such thing as the financial positions of participants can vary greatly and individual planning outside the framework of the training seems more appropriate.

Before the actual training started an information session was organized for staff and family in which attendants were told about later life options for adults with ID and ways to support their clients and family members in making choices and attaining goals. This introduction session also provided specific information about aging and intellectual disabilities.

Each curriculum training session takes about two hours, including a short break. It is best to plan for one session every week at a fixed day and at a fixed time. Apart from lessons One and Two every other lesson starts with a discussion of the “Choice maker Chart”. This includes discussions and questions such as: “What choice did you make this week, could or couldn’t you make it, why not and what will your choice be for next week?” In the beginning every choice is good as long as the principle of choice making is clear; eventually the choices become more complex as the items discussed in the curriculum become more complex.

From Lesson Two onward, the Homework of the previous lesson is discussed. This gives the (co) trainer the opportunity to rehearse and recapitulate and check if participants understand and remember the items discussed earlier.

Lesson One starts with an introduction of the participants and of the trainer and co-trainer. Sometimes participants are familiar with each other; sometimes they are not in which case an introduction is needed. Then, by showing the posters, the (co) trainer explains the six central themes of the training - Choice Making, Exercise and Healthy Choices, Free-Time Activities, Friendships, Work/Retirement and Places to Live - asks each participant in what theme he or she is most interested. To facilitate a discussion on the many aspects connected with aging the Life Span Line is introduced. Participants are asked with what picture life starts - with the baby picture - and with what picture life ends - with the pictures of a granny and a grandpa: they are indeed very, very old. In order to finish the Life Span Line, the (co) trainer asks at random, where to place the pictures of the kindergarten- and schoolchild, the teenage boy and girl, the young father and mother, the older father and mother and the grandparents. In a combined effort of the whole group the Life Span Line is put together. During the break the co-trainer can take every participant’s Polaroid picture. The idea is to ask to put that picture on the Life Span Line with the same age person. It is noteworthy that many older adults with ID put their picture next to the young father or mother, never mind the fact that their hair is gray and their face wrinkled.

In Lessons Two and Three the process of Choice Making is explained and how important it is to make choices concerning the important things in life: where to live, what to do in your free time and where to meet friends. Rights and associated responsibilities is the next rather abstract item to explain. The (co) trainer is wise to make this subject as concrete as possible. On a poster-size paper the word “Rights” can be written on top of the left side of the paper and “Responsibilities” on top of the right side. Participants are then asked what they may do and what they, consequently have to do. Another way to explain is to have participants role-play their rights. It is important for the (co) trainer to know if participants are familiar with choice making, information that can be obtained through the individual care person of each participant. With this information the training can be personalized and optimized to ensure maximum understanding with the trainees.

Lessons Four, Five and Six deal with Healthy Choice Making and Exercise. The purpose of these three lessons is to make participants aware of changes that occur when people age. Other issues are the importance of - daily - exercise and making healthy choices in order to maintain good health. Participants learn about the major organs - heart, lungs - how the body ages - difficulties with vision and hearing, for instance - what one can do to keep in shape and how one can be responsible for one’s health. Posters of the human body can be shown and participants are invited to do simple exercises, if possible with music.
After these three lessons participants must know why it is important to do exercises and name a few exercises they can do. They must also know the right clothes to wear while exercising and why it is important to warm-up.

Free-Time Activities are discussed in lessons Seven and Eight. In these lessons participants are made aware of the importance of free-time activities and of activity versus inactivity. After finishing the lessons participants are able to tell why it is important to do interesting things and remain active in leisure time. They also learn about various leisure time activities they can engage in the (near) future with as little help as possible. A very appealing part of this part of the training is the field trip participants plan.
In offering them a (limited) range of choices the (co) trainer can offer them a real opportunity for choice making. From the choices available they may also gain information about other future field trips they may make with family or friends. The field trip must be a positive and rewarding experience for all trainees.

Work, Retirement, and options for part-time or full-time work are discussed in lessons Nine and Ten. Participants are told about the shift over the years from full-time to part-time jobs and eventually, retirement. It is important that persons make up their mind about what they really want and what is possible under the circumstances. The (co) trainer should explain the various reasons why people want to go to work full time - to earn enough money -, to work part-time - to keep in touch with friends - or retire - too old and too tired to work. It may be useful to invite a guest speaker who has already changed his or her work rhythm to the lesson; participants can ask then what it is like to work less or be a full pensioner.

The importance of Friendships and Social Networks is the central issue in Lessons Eleven and Twelve. Friendships and good social networks are essential in aging well (see Chapter I). Often transportation is a big impediment and persons with ID may be “forced” to look for friends close to the place where they live. In this phase of their life, now they may expect to have more leisure time and more possibilities to do things, they must learn to rely upon existing friendships and try to make some more. Through role-plays participants learn in these lessons how to make new friends and maintain old and new friendships. The necessary social skills are practiced and people learn how to speak out for themselves. They learn how to discriminate between friendships - from a true pal to a faint acquaintance - to describe their networks of family and friends and how to tackle problems that may arise in this field.

Lesson Thirteen Volunteering informs participants about the concept of volunteering in the community and encourage them to consider volunteering as a leisure time option. Doing volunteer work in the community is a very mainstream activity in the United States, with volunteers representing every segment of society; with literally millions of people over the age of 60 years are community volunteers. Sometimes participants find it difficult to understand the concept of working without pay; to overcome this difficulty a person with ID who is a volunteer can be asked to tell in class his or her experiences and the pleasure he or she gets out of it.

Lessons Fourteen and Fifteen deal with the various Places to Live. The aim of the lessons is to inform participants of the many options for living and the pros and cons of every setting so people can make an informed decision on the place of their choice. A second goal is to find (material) ways to improve the place where participants live, for instance by drawing a picture for the sitting room. In discussing the way people live together in their house - how they divide the household chores among themselves, for instance - the (co) trainer can hint at possibilities to optimize the atmosphere.

The last two lessons are geared to the (new) learned choice-making skills of the participants. In lesson Sixteen the trainees are helped to set their goals and learn how they can stand up for themselves in Care Plan Meetings. During the training the participants learned about the various options for work or retirement, how to make and keep friends, choices in healthy food and daily exercise and in living arrangements. More often than not older people with ID have had little opportunity and practice to speak out for themselves, and often lack self-confidence when sitting opposite staff. This one lesson cannot redress a lifelong dependence, but offers an excellent opportunity to experiment with new behavior in this field.

In lesson Seventeen each participant gets help from the (co) trainer in formulating their Action Plan, the most important tangible outcome of the training, in terms of choices made during the various lessons. Some of these choices can be found in the Workbook of the student. The Action Plan should be used as the basis for the Individual Service Planning Meeting. At the end of this lesson participants get their certificate as a token for their achievement in capturing the most important lessons of the training. Family members, friends and staff of the trainees should best attend this festive closure of the training. It is important to give participants a fair choice in its preparation - what to wear, who to invite, what to serve and what music to play during the ceremony.

4.2 The most important elements of the curriculum

Because sometimes individual help is needed during the lessons - for instance in understanding the instructions in the Notebook - it is important to have a team of a trainer and a co-trainer to present the lessons. While the trainer oversees the lesson, the co-trainer can attend to the individual needs of the trainees.

The trainer and co-trainer should be familiar with the content of the lessons and prepare themselves well, but it is the imagination of the (co) trainer that brings the curriculum to life and guarantees the actual learning process of the trainees. In their attitude and enthusiasm they serve as a role model to the participants. The trainer might be a person who does not know the participants, but who is familiar with teaching (older) persons with ID. The co-trainer is best a person, who is familiar with participants, is known by them and is aware of their special needs. In introducing a familiar person in the classroom, trainees might be less reluctant to participate in the training. To ensure integration of the learned concepts into their daily lives it is essential to assign an individual care person to each trainee. This person should be the one that is most familiar, or has the most contacts with the trainee, be it in the place he or she lives in or in his or her working place. In an ideal situation the trainee chooses his or her individual care person.

Before the actual training starts individual care persons and family members are invited to a special meeting in which the trainer explains the purpose and the goals of the curriculum. This is also be a good opportunity to present the co-trainer.
The personal care person has the following tasks:

- To attend the introductory meeting with family members and other care persons;
- To be aware of the content of the training program;
- To check after every lesson the relevant page in the Notebook and possible information in the Reminder Envelope;
- To help the trainee with his or her homework;
- To help the trainee doing his or her physical exercises and familiarize the newly learned concepts;
- To offer choice-making opportunities and give information to enable the trainee to make informed choices;
- To check the Notebook on a regular basis;
- To encourage the trainee and remind him or her to do things that was asked in the lessons.

The trainee gets a Notebook with pages corresponding to the various lessons. At the beginning of each lesson the relevant page(s) are commonly checked, which ensures a short repetition of the most important newly, learned concepts of the previous lesson. At the end of every lesson the relevant page(s) are given to clip in the Notebook. This Notebook should be an attractive, brightly colorful one that the trainee keeps after the training is finished.

To practice what was presented in the lessons reminder notes are placed in the Reminder Envelope, which is given at the end of every meeting. In this Envelope the (co) trainer also places important information for the next lesson - like “Don’t forget next time to bring your training shoes!”. The information can be general - as in the example cited - or personal as in “John was coughing all the time - perhaps he will fall ill.” The success of the strategy of the Reminder Envelopes depends very much on the trustworthiness of the assigned individual care person. He or she should check the Envelope after every lesson and ensure that the instructions therein are followed up.

The most important goal of the curriculum is to teach participants the skills necessary to make informed choices and their rights concerning choice making. The best way to achieve these skills is through daily practice: many exercises in the Notebook are meant to do exactly that. This includes filling out the Choice-Making Chart at the beginning of every lesson and checking every next lesson to see if the written down choices are made indeed. The Chart becomes the red thread throughout the training program. Participants are made aware of all the choices they have throughout the day - have coffee or orange juice, wear a blouse or a sweater, wake up early or sleep in - which the individual care person should help them make. In the beginning of the training the choices may be simple - as in the examples - later on choices may become more complicated: questions answered include “Do I want to live on my own, do I want to retire or work part-time etceteras”. In this respect the Choice-Making Chart is an illustration of the progress the trainee has made during the course.

Various visual aids - like video’s, posters, pictures and drawings - are-used during the training. These visual aids are essential because persons with ID seldom only rely on their hearing to obtain and store information. As was explained earlier (see Chapter II) in teaching persons with ID new concepts it is best to appeal to all faculties: vision, hearing, taste, smell and feel. Therefore attractive visual and audio aids as well as music to dance by - or to relax with - and tasty snacks, coffee or tea during breaks all provide a pleasant atmosphere in which participants are invited to learn new things and expand their horizon.

Chapter IV presents the results of the research done in the US (Sutton et al., 1994) to establish the validity of the concepts and thoughts underlying the curriculum “Later Life Planning for Adults with Mental Retardation” as well as its actual format - instructor’s script and guide, student’s notebook, graphics, choice-maker chart and reminder envelope - as explained in this chapter.

Chapter V

Results of training the curriculum “Later-Life Planning for Adults with Mental Retardation” in the US

The curriculum was extensively researched in the US (Sutton et al., 1994). The first version was pilot-tested on a sample of 54 older adults (age 50 or older and 35 and over for those with Down Syndrome) with ID in Illinois and Ohio. Trainees participated in vocational programs at several sites in the greater Chicago area and in Summit County, Ohio. There also was a comparison group of 49 older adults with ID at similar sites in Illinois and Ohio.

The two aspects of this first intervention study were:
1. a planning content component that focused on later life planning issues and options,
2. a planning process component that focused on individual empowerment issues and skills.

The curriculum incorporates an approach to planning that:
1. recognizes the importance of involving persons with ID and their families in life span planning;
2. emphasizes that choices are to be made based upon reliable and comprehensive information;
3. utilizes generic aging network services when appropriate to provide community integration with peers and to avoid duplication of services;
4. presents program options beyond the traditional developmental disabilities service system.

The intervention program evaluation addressed the following research questions:
1. What is the impact of training in personal empowerment and later life planning on life satisfaction, leisure and recreation activity, social support resources, and opportunities for daily choice making of adults with ID over a period of six months?
2. What is the impact of this training on knowledge regarding personal choice making and retirement options?
3. What is the impact of training in personal empowerment and later life planning on the planning process itself, including the congruence between the individual’s stated goals and their individual service plans, and the individual’s degree of participation in individual service planning meetings?
4. To what extent does the training program affect staff’s behaviors at individual service planning meetings in terms of facilitating choice making among older adults with mental retardation?

To find an answer to the first and second research questions baseline assessments (T0) were conducted before the actual training program started. Assessments to establish training effects were performed within three (T1) and six (T2) months after participants finished the training.
The first two research questions were addressed through, respectively the “Later Life Planning Inventory for Older Persons with Mental Retardation / Developmental Disabilities” (LLPI) and the “Later Life Planning Curriculum Pre-Test / Post-Test for

Older Persons with Mental Retardation / Developmental Disabilities". The LLPI is conducted through an interview with each participant and includes a measure of his or hers life satisfaction, leisure activities, social support, daily choice-making and personal preferences. The second test - also an individual interview - measures knowledge of aging and later life planning options as taught in the curriculum.
Dr. Tamar Heller at the Institute on Disability and Human Development, University of Illinois at Chicago developed both instruments.

The impact of the training in personal empowerment and later life planning - research question number three - was observed during the first service-planning meeting following the training. With the help of the Habilitation / Service Planning Observational Tool - an instrument specially developed for this project - project staff assessed students' individual participation and the degree to which regular staff did facilitate choice and preferences of the former students. Written goals and action plans resulting from this service-planning meeting were assessed in order to find an answer to the fourth research question.

To establish relevant demographic data on the persons participating in the training, including level of ID, staff was asked to fill out the ICAP (Inventory for Client and Agency Planning, Bruininks et al., 1986).

Participants' level of ID ranged from mild (46%) to moderate (44%) to severe (10%); their ages ranged from 36 to 88 years. In the analyses of the training results only the scores of the persons with IQ's in the mild and moderate ranges were evaluated, as the assessment instruments were not geared to reliably measure the scores of persons with severe ID.
The research finding reported by Sutton et al. (1994) indicates that after the training:

1. Participants had an increased knowledge of aging and choice-making options;
2. Participants wanted to live on their own or wanted to move in with their family;
3. Participants living with their families were more involved in leisure time activities;
4. Service Planning Meetings of participants (as opposed to controls) were more likely to:
   - include family members
   - take into account the perspective of the person with ID
   - show a greater staff engagement when the trainee's desires, past goals and
   - action plans were discussed.

On the basis of these findings the following adjustments were suggested:

1. choice-making should be practiced throughout the training;
2. right from the beginning of the training an individual support person should be assigned to the trainee to help him or her implement what is learned in the lessons;
3. more role-plays and feedback regarding the trainee's ability to advocate for oneself should be build in;
4. more often peer trainers should be invited to serve as role models and mutual support;
5. more visual aids, simpler language and more experiential exercises should be used;
6. the module on friendships and support networks was expanded.

In research published later (Heller et al., 1996) the sample expanded to include 70 persons; 42 were included in the program (intervention group) while 38 were not (reference group). They were all adults with ID age 35 and over with Down syndrome and adults with ID age 50 and over without Down syndrome. Assessments with LLPI and the Curriculum Test were performed before the training started (T0) and six months later when the subjects were trained (T1). Observations of individual service planning meetings were also included in the evaluations. Staff persons filled out the ICAP; in the analyses only the demographic data were used.

The major goals of the training were to:

1. increase participants’ knowledge of later-life options;
2. facilitate greater individual choice and participation in decisions affecting his or her life;
3. facilitate setting of realistic goals by the participants
4. increase or maintain his or her wellness behaviors;
5. increase participants participation in leisure time activities, including volunteer activities in the community;
6. increase individual life satisfaction;
7. change staff behavior to facilitate greater encouragement of personal choice making among older adults with ID.

In the article the following results are presented (Heller et al., 1996):

1. Before the training started at least 60 percent of the participants had no choice about the type of work they do, while more than 25 percent of the individuals reported they have no choice in making choices about routine daily activities, for example what to eat, when to use the phone, and whether or not to clean or decorate their rooms; after the training participants showed an increased knowledge in choice-making and aging.
2. After the training the intervention group also showed a significant increase in knowledge on nine out of fifty-two items of the LLPI test; the comparison group showed a decrease in knowledge. Five items pertained to leisure information, three items informed after knowledge of retirement, work and volunteering, and one after social support. There were no significant improvements in the knowledge on items pertaining to making choices and action plans, health and wellness, and living arrangements. In other words, trainees were able to grasp the concepts of retirement and volunteer activities but had more difficulty understanding the idea of health promotion, residential options and their choice making rights and responsibilities.
3. An unintended consequence of the training was a decrease in total life satisfaction with the intervention group, while the comparison group increased in life satisfaction. This was primarily attributed to lower satisfaction with their residential settings. After hearing about other potential options several adults who lived at home and several who lived in more restrictive settings such as nursing homes and larger intermediate care facilities wanted to move out. Increased awareness of options, comparison of their preferences with their currents status and raised expectations may have resulted in feelings of dissatisfaction, but at the same time likely created the agenda for action. If indeed the training results in long-term improvement in living situations, then the short-term effect of residential dissatisfaction is a necessary first step in this transition.

4. Participants showed a greater desire to move in with their family or to live independently.
5. Students living with their families showed a greater participation in leisure time activities; the only significant increase over time for specific leisure activities among the in-home intervention group was in volunteer activities - from 28% to 74%. Their options for getting involved in their preferred leisure activities were much more limited.
6. One of the major successes of the training was its influence on the individual service-planning meeting. Compared to controls participants' families more often attended the meetings, staff encouragement of the individual was greater and more of his or her wishes ended up in the written service plans. These findings are attributed to a greater involvement of family and staff throughout the training through the homework assignments and their presence in the goal setting session. The trainees themselves however did not speak out more during these sessions. Apparently the difference between a safe classroom setting and the real world with professionals inhibited them. The authors suggested that more role-playing of individual service plan meetings during the curriculum might be an answer to this problem.

Although these research findings are very rewarding and show that older persons with ID can indeed benefit from the curriculum some questions remain unanswered. One is an explanation of the lack of significant changes in individual choice making. An explanation is possibly found in the relatively short period in which the data were collected. Perhaps a longer time period is needed to measure changes.

On the basis of this research some improvements were suggested, the first of which was that in order to facilitate generalization to everyday situations more role-play opportunities should be built in into the sessions. Another important step to promote a positive outcome of the course is to get full support of the service provider to train staff so they will be better prepared for the changes within their clients and grant permission for every participant to have a support person available right from the start of the course. The revised version of the Later-Life Planning curriculum was researched again in the late 1990's. The results were published in the article "Later-life planning: promoting knowledge of options and choice making" (Heller et al., 2000).

The revised curriculum addresses the same subjects as the original curriculum and has the same goals. In the study discussed here quantitative data analyses were used to examine whether participation in the curriculum would lead to an increase in:

- knowledge regarding personal choice-making and retirement options;
- the amount of choice
- and the overall life satisfaction of the participants.

Qualitative data analysis was used to establish what kind of goals participants made, the degree to which they met these goals and the supports and barriers for meeting the goals.

Participants were 60 persons with ID who had to meet the earlier mentioned criteria and who were recruited from Illinois and Ohio; 38 of them were in the intervention and 22 in the comparison group. There were no significant differences between them in terms of age, gender, race, and level of ID, type of residential or vocational setting.

The research design was essentially the same as described earlier: pretests were done one month prior to the training and the posttests one month after finishing the training. They included the Later-Life Planning Curriculum Test, Life Satisfactory Scale and the Daily Choice Inventory. The training was conducted on a weekly basis for four months.
Two months after the training information was gathered on the specific goals participants set in the last training session; ten months later data were collected on whether these goals were met and what specific supports or barriers participants experienced in trying to attain their goals.

The results show a significant increase in the mean curriculum knowledge score for the intervention group over the comparison group, as well as an increase in the amount of choice over time (see Heller et al., 2000). There was no significant main effect of life satisfaction over time or significant differences between intervention and comparison groups, although the first slightly increased in life satisfaction and the latter slightly decreased; the differences not being significant.
In terms of set goals, the most goals were social-recreational activities, maintaining or changing their employment and housing situation and improving health and well-being. In terms of goal attainment, 55.2% met expectations, 28.7% partially did so and 3.4% and 12.6% respectively exceeded and did not meet expectations (see Heller et al., 2000). Support came from staff and family, and availability of transportation was essential to get to places. Barriers were physical and cognitive limitations and lack of money.

As in earlier studies (Sutton et al., 1994; Heller et al., 1996) this study also indicates that a later-life training curriculum can teach older persons with ID subjects like health and well-being, leisure activities, work and retirement and living arrangements. In addition participants in this study gained a greater understanding of the concept of choice. In short, consistent with the life-span developmental perspective, the present findings show that adults with ID are able to gain knowledge and skills as they age (Baltes & Graf, 1996).
Compared to earlier findings (Heller et al., 1996) through the revised training program in which more role-plays and a support person were introduced, participants made significantly more choices. As can be seen from the data gathered before the training started, older adults with ID only have limited choices available to them. According to research (Wehmeyer & Metzler, 1995) adults with ID are likely to be allowed to participate in choices and decisions about their lives that are of relatively low importance, such as what they wear, but are not likely to be involved in more important decisions, such as the type of work they have or the place they live in.

Participation in the training did not enhance life satisfaction, as might be expected on the basis of earlier research (Mahon & Goatcher, 1999). But the fact that after a ten month period about 55% of the participants did fully meet their goals and about 29% did partially meet their goals might indicate that life satisfaction was measured too soon after finishing the training (one month) when the difference between the observed present state and the wished future state was too great and that - after some time - there might be a higher level of satisfaction in the intervention group.

Because of the very promising results of the curriculum “Later Life Planning for Adults with Mental Retardation” that were found in the US, a group of researchers working for the Institute of Psycho Social and Epidemiological Research - a research institute affiliated with Maastricht University - thought it very compelling to duplicate the research in the Netherlands. Chapter VI describes the results of the training “Cursus Ouderdomsplanning voor Mensen met een Verstandelijke Handicap”.

Chapter VI

Results of training the curriculum “Later-Life Planning for Adults with Mental Retardation” in the Netherlands

Introduction

In order to be able to compare the results of the research done in the US (Sutton et al., 1994; Heller & Factor, 1996) the design of the study was duplicated in the Netherlands. The English questionnaires and training materials were translated into Dutch and after data collection the same research methods were used. The selected trainers were instructed beforehand in a two-day training session by professor Tamar Heller of the Institute on Disability and Human Development of the University of Illinois at Chicago.

The research presented in this chapter will deal with the answers to the following two questions:
What are the effects of training the curriculum on participants’ choice-making knowledge and attitudes regarding health and well-being, leisure time activities, work and pension, living arrangements, choice making and involvement in Individual Service Plan (ISP) meetings?
What are the effects of the training on participants’ satisfaction with leisure time activities, living and work arrangements?.

In the Dutch curriculum the Chapter on Volunteering is missing. As was already stated in Chapter IV: “Doing volunteer work in the community is a very mainstream activity in the United States, …”. In the Netherlands however, volunteering is not that wide spread and is only very rarely done by persons with ID, which is why this chapter was removed from the Dutch version of the curriculum.

Because of the same small differences in culture some of the original American graphics and drawings were “translated” into photographs and posters that were more fitting to European circumstances. An American high-rise - as an opportunity for future living in Chicago - for instance, became a two-story building and playing horseshoe - as a leisure activity - became playing billiard.

As a last adaptation the last two lessons - “ISP-meetings and Goal Setting” and “From Goals to Action Plans” - were changed from two group sessions to one individual session in which trainer, co-trainer, the participant and his or her case manager reviewed participant’s wishes in all domains the curriculum addresses. The reason for this change being that - in the researchers opinion - the concentration of participants would be unduly overcharged if every group member would be obliged to listen to every other group member’s goals and wishes.
If possible, relatives and/or friends were also invited to be present. As the relevant research literature amply indicates, family and friends can be of great importance in helping their relative or friend to attain the goals stated.
In the Netherlands the training ended with a festive ceremony in which the students got a certificate, signed by the teacher and, if possible by themselves. For most

participants this happening was very rewarding: for some it was the first time in their lives they got a certificate at all.

6.1 Methods

As much as the Dutch project wanted to duplicate the US research design, it must be noted that research questions three and four (see Chapter V) because of limited financial resources could not be dealt with and therefore the Service Planning Observational Tool was not used in the Netherlands.

The first research question was tackled with the “Later Life Planning Curriculum Test” (LLPC) (see Appendix I) from which the questions regarding “Friends” and “Volunteering” were skipped, which leaves 28 instead of 33 questions to be asked. The item score is as follows: ‘0’ means no correct answer, ‘1’ means one correct answer and ‘2’ means two or more correct and relevant answers. The 28 items deal with the six remaining main themes of the curriculum. On “Health and Well-Being” the score ranges from 0-4; on “Leisure Time Activities” from 0-15; on “Work and Pension” from 0-9; “Living Arrangements” from 0-4; “Choice-Making” from 0-4; “ISP-meeting” from 0-4 and “Exercise and other healthy choices” from 0-10.

To find an answer to the second research question the “Later Life Planning Inventory” (LLPI) (see Appendix II) was administered; it measures participant’s satisfaction in five domains; the item score ranges from ‘0’, not satisfied to ‘2’, satisfied. The five domains are: “Leisure Time Activities” (score ranges from 0-4), “Living Arrangements” (score from 0-10), “Social Network”(score from 0-8), and “Work Arrangements” (score from 0-10).

The LLPI (Heller et al., 1996), which is conducted trough an interview with the individual, is an inventory which includes the Life Satisfaction Scale, which was adapted from the Life Satisfaction Scale for Aging Adults with Mental Retardation (Hawkins et al., 1992); the Leisure Inventory (Hawkins et al., 1992); the Social Support Network Index (Heller & Factor, 1992); and the Daily Choice Inventory. A test-retest (using pearson correlations) was conducted on the measures newly developed for the project with 13 of the subject randomly selected. The same questions were administered twice, two months apart. The Life Satisfaction Scale includes 21 items in 5 domains: 1) health, 2) leisure/recreation, 3) work, 4) residence and 5) social support. Items are rated on a three point scale from -1 (unhappy with current situation) to +1 (happy with current situation. Alpha reliability on the current sample was .82. The alpha reliabilities on the domain subscales were moderate to high, ranging from .50 to .82. The test-retest was .83 for the total score. With the exception of the health work domains, which had low test-retest reliability, the domain coefficients ranged from .58 to .84. The Leisure Inventory consisted of 50 activities in which persons are asked whether they do the activity “more’, “same”, or “less”, and if they are not currently doing it whether they would like to do it. Photographs are used to illustrate each activity. The alpha reliability on the measure of activities they are currently doing was .92. The Social Support Network Index asks the persons if they get help from parents, other relatives, friends or staff in nine support functions. The alpha reliability was .48 and the test-retest was .95. The daily Choice Inventory included 12 items in which persons are asked to what extent they get choices. Responses range from “never” to “whenever I want to”. There was an additional item that checks for acquiescence and is not used in the analyses. The alpha reliability of the scale was .86.

Some demographic data of the participants - age, gender and level of ID - were obtained through a revised form of the “Inventory for Client and Agency Panning”, the ICAP for short, developed by Bruininks et al. (1986) (Appendix III). The same questionnaire was also used to get information about participants’ present living arrangement, day activities, participation in social and leisure time activities and barriers that might prevent participation like not being interested, lack of staff, no transportation, and financial, health and/or behavioral problems.
Participants were interviewed at three different times: before the training started (T0), directly after the training (T1) and three months after finishing the training (T2). The average interview time was about 45 minutes; students of the University Maastricht, previously trained as social workers or nurses and a special educator, performed the interviews.

Participants in the training were recruited through various organizations in three Dutch provinces: Limburg, Utrecht and Gelderland. Students lived on their own or with family members, in pavilions in institutions or with three to twelve persons in houses in the community. All persons who wanted to participate gave their informed consent. Because only a limited number of trainers were available and 153 persons wanted to participate the group was divided into two by asking if persons wanted to wait for a second round. This resulted into two groups: 98 persons were in the intervention group and 55 persons were in the reference group. The second group also got the training, but at a later stage. The intervention group was interviewed at three different times: before the course started (T0), after the course (T1) and again three months later (T2). The reference group was interviewed twice: at T0 and T1. T2 could not be done with persons in the reference group because - as promised - several new groups had already started.
The curriculum was presented to thirteen groups, each varying from five to eight persons.

6.2 Characteristics of participants

In table 6.1 some characteristics are presented of both the intervention and the reference group before the actual course started. These characteristics involve gender, age, level of ID, present living arrangement, occupational/day activities, social/leisure activities and barriers for participation in social/leisure activities.

Table 6.1 shows significant differences between the intervention and reference groups regarding to gender and level of ID: in the intervention group 34% are male and 66% are female, whereas in the reference group men count for 51% and women for 49%. So men are clearly under-represented in the intervention group. With regard to level of ID there are also significant differences: in the reference group are more persons with a moderate ID than in the intervention group (36% versus 17%). As a consequence, the results and effects will be described separately regarding men versus women and persons with moderate versus persons with mild ID.

Table 6.1 A comparison on characteristics between the intervention and reference group (%).

	Intervention group (N=98)	Reference group (N=55)	Total group (N=153)
Gender			
- male	34%	51%	40%
- female	66%	49%	60%*
Age (in years)			
40 - 49	9%	4%	7%
50 - 59	38%	46%	43%
60 - 69	32%	33%	34%
70 - 79	20%	11%	13%
80 - 89	1%	6%	3%
Level of ID			
- mild (IQ: 52-70)	83%	64%	76%
- moderate (IQ: 36 51)	17%	36%	24%*
Living arrangement			
- Independent living	44%	42%	43%
- independent living with support	20%	16%	19%
- living in an institution	36%	42%	38%
Occupational/day activities			
- no	16%	11%	14%
- yes	84%	89%	86%
Social/leisure activities			
- no	4%	5%	4%
- yes	96%	95%	96%
Barriers for participation in social/leisure activities			
- no	44%	40%	43%
- yes	56%	60%	57%

* Chi-square; p < .05

The age range in the total group was from 40 years to 87 years; the youngest person in both groups was 40 years; the oldest person in the intervention group was 81 years and the oldest person in the reference group was 87 years. The mean age of persons was 60.0 years in the intervention group, 60.4 years in the reference group and 60.2 years in all persons participating; de standard deviation was 8.9, 9.4 and 9.0 respectively.

Table 6.2 A comparison between levels of ID in the intervention (N=98) and reference group (N=55).

	Intervention group		Reference group	
	Mild ID (N=81)	Moderate ID (N=17)	Mild ID (N=35)	Moderate ID (N=20)
Gender				
- male	36%	24%	51%	50%
- female	64%	76%	49%	50%
Living arrangement				
- independent living with support	64%	47%	66%	35%
- living in an institution	36%	53%	34%	65%

Considering the living arrangements between the intervention and reference groups not many differences can be found: 44% of the intervention group and 42% of the reference group live independently. Independent living arrangements include living with parents or other family members, lodging (room and meals, without any professional support), living with foster parents, renting or living in one’s own home. Twenty percent of the persons in the intervention group live in-group homes, whereas only 16% of the reference group does; 36% of the persons in the intervention group and 42% of the persons in the reference group live in institutions.

Before the training started support persons (professionals or family members) were asked to fill those parts of the ICAP that had to do with occupational or day activities, social or leisure activities and existing barriers for participation in the latter activities. More than 80% in both groups (84% and 89% respectively) participate in structured day activities, away from living quarters. Activities may include daycare, visiting a day activity center, training on the job, working in sheltered workshops or holding normal jobs with or without support. Almost everybody (96% and 95%) has regular social or leisure activities like, visiting family or friends, shopping and running errands, dining out alone or with friends, visiting clubs or engaging in hobbies alone or in a group. In more than half of the persons in both groups (56% and 60%) there are barriers that prevent people from participating in social activities. These impediments may include (see table 6.3.) health problems, lack of staff, and no interest, lack of transportation and/or finances and behavioral problems. In this respect there were no statistically significant differences between the intervention and reference group.

Table 6.3 Existing barriers: intervention group versus reference group.

	Intervention group (N=98)	Reference group (N=55)
- Health problems	17%	17%
- No staff present	14%	15%
- Lack of interest	14%	11%
- No transportation	11%	9%
- Lack of money	8%	11%
- Behavioral problems	5%	7%

Thanks to good personal contacts between co-trainers and participants - the co-trainers were persons who were familiar to participants - the number of persons that did drop out was remarkably small. In the Dutch study from T0 to T3 only ten persons out of the original 98 left the project. For various (undisclosed) reasons seven persons left before the course started. At T2 one person was in the hospital and two persons refused to take a third interview - reducing the total number of persons involved in T2 to 88 persons.

6.3 Communicational problems when interviewing persons with ID

Before presenting the actual research results it is worthwhile to reflect shortly on the manifold communication problems one may encounter when interviewing persons with (moderate) ID. (Derks et al., 1994). Apart from a limited vocabulary, a person with ID may have problems in abstract and conceptual thinking. All of this calls for the use of simple words and concrete questions whenever talking to a person with ID. Because of anatomical anomalies or cerebral palsy it is sometimes hard for the interviewer to understand a person. Hearing problems may make it difficult for a person with ID to grasp what the interviewer is saying. At other times the interviewee may feel uneasy, too uneasy to concentrate for a certain amount of time, or may be too fixed upon certain subjects so that he or she cannot focus upon the question asked. A final complication may be the presence of behavioral or mental problems in the interviewee.

The interviews often took place in participants' bedrooms or living rooms - there they felt comfortable enough to answer the questions. When visiting the interviewees, a staff member often was around in the home. Staff often would answer the door and introduce the interviewer to the interviewee, thus creating a comfortable atmosphere. Often there was coffee to help make the interviewee (and the interviewer) feel at ease and offer ample time for a break in between questions. The questionnaires were specifically developed for persons with ID, so questions were mostly attuned to the interviewee's conceptual level and questionnaires could be asked within an hour's time. If a person did not understand the question it was rephrased or - if no appropriate answer was given - the answer was scored as not right, incorrect or irrelevant.

6.4 A comparison of the effects of the curriculum on choice-making knowledge and attitudes before and directly after the training

The first research question is: "What are the effects of the curriculum on participants' choice-making knowledge and attitude regarding health and well-being, leisure time activities, work and pension, living arrangements, choice making and involvement in Individual Care Plan (ICP) meetings?"

In order to be able to establish the effects of the curriculum sessions in a reliable way and to exclude possible accidental results future students were asked if they wanted to participate in the first round of courses or in the second round. A second constraint was the limited number of trainers available. Both conditions resulted in 98 persons who could start in the first round before the summer holidays - the intervention group - and 55 persons waited for the second round to start in September - the reference group.

All students got the baseline interview (T0) in February - March 1998, shortly before the start of the courses. The T1 interview was planned within three weeks after the intervention groups had finished their learning in the summer of 1998, the interval period between T0 and T1 being less than five months.
At T1 there were 91 persons in the intervention group - seven persons (7%) had stopped during the training because of illnesses or lack of interest. In the control group there were 45 persons at T1 - in the mean time ten persons (18%) had either lost interest, moved away or refused the second round of interviews because they couldn't enroll in the courses before the summer.

In the following tables the mean score for the intervention group and the reference group are presented for every domain mentioned in the first research question - health and well-being, leisure time activities, work and pension, living arrangements, choice making, and involvement in ISP meetings - at T0 and T1. The data are specified according to gender, level of ID and living arrangement. In separate columns (%) is indicated how the mean score changed - in a positive or negative way - from T0 to T1.

6.4.1 Choice making

Over the last years persons with ID are ever more invited to make choices on how they want to shape their (future) lives. Their choice making abilities however and a clear idea on their rights and plights are often absent or at least vague. The chapter “Choice making” focuses on these items and participants learn the importance of making their own choices concerning the various aspects of their lives. Choice making is a leading theme throughout the curriculum. Every lesson - from lesson three onwards - begins with a discussion of the Choice Making Chart: what choice did every individual participant make this week, why this choice and what will next week’s choice be? Were participants able to follow up their choice(s) and if not, why not? In this quite natural way choice making abilities are trained in every lesson.

Table 6.4 Choice making knowledge (score 0 - 4): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45).

	Intervention group			Reference group		
	T1	T2	%	T1	T2	%
Total	1.78	2.26#	+30.0	2.63	2.48	-5.7
Gender						
male	2.13	2.13	0.0	2.68	2.08	-22.4
female	1.60	2.32#	+45.0	2.57	2.95	+14.8
level of ID						
Mild ID	1.80	2.30#	+27.8	3.34	2.41	-27.8
Moderate ID	1.67	2.00	+19.8	1.41	2.59#	+83.7
Living arrangements						
Independent living with support	1.76	2.69#	+52.8	2.78	2.83	+4.7
Living in an institution	1.76	2.29	+30.0	1.75	2.50	+42.9

matched t -test: p< .05

In general participants’ mean score on knowledge of choice-making increased significantly during the training period whereas the mean score for persons in the reference group declined (Table 6.4). When taking a closer look at the score of the male versus the female participants one sees that the male students gained no knowledge on this subject while the female students show a major increase in their knowledge. Table 6.4 also shows that persons with mild ID and persons living independently with support gain significantly more knowledge on this subject. Interestingly enough persons in the reference group with moderate ID were also significantly more knowledgeable at T1.

Before and after training on the curriculum persons in both the intervention and reference groups were asked if they themselves had a choice on twelve aspects of daily living or if somebody else made that choice before them (see table 6.5).

Table 6.5 shows an increase in most of the above choice-making opportunities for persons in the intervention group; there is a decrease however in “how you spend your money?” and “when do you clean your room?” The conclusion is in accordance with research findings (Wehmeyer & Metzler, 1995): in things that matter (like money spending and hygiene) persons with ID tend to have little choice-making opportunities. The course helped participants (see table 6.4) learn how to make more choices. The results for the reference group are less conclusive: on some items the score is higher at T1 compared to T0, and on others the score drops between T0 and T1. Generally, interviewees could choose what things they do in their free time, and what TV shows they watch; choices on the other items greatly differ between the two groups and between the two times of measurements.

Table 6.5 Choice making: comparison in percentages of the results of the intervention (N=91) and reference group (N=45).

	Intervention group		Reference group	
	T0	T1	T0	T1
Do you, or does somebody else, get to choose? "I do" says:				
- what food you eat?	71	77	65	69
- what clothes you wear?	88	95	77	73
- what things you do in your free time?	94	97	94	95
- what TV shows you watch?	95	99	91	91
- how you spend your money?	75	72	62	58
- when to go out with friends?	92	94	89	78
- what time you go to bed?	96	97	83	76
- how do decorate your room?	91	93	89	73
- when you clean your room?	69	60	58	47
- when you have guests visiting your room?	92	97	78	96
- what job you have or what work you do at your workplace?	82	85	63	52

6.4.2 Health and Well-Being

In the lessons on Health and Well-Being participants learn about the physical changes they may encounter when aging and about making healthy choices in terms of the importance of doing physical exercises in order to keep their blood pressure and weight under control and eating healthy foods with low fat, and with only little salt and sugar. They learn that in making healthy choices they can maintain a good health and well-being.

Table 6.6 shows the changes in knowledge of health and well-being for the total of the intervention and control groups, but also according to gender, level of ID and living arrangement. The graphics show a significant increase in the knowledge of the intervention group as a whole and in all six subgroups on health and well-being compared to the control group.

Table 6.6 Health and Well-being (score 0-4): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45).

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	1.77	2.29#	+29.4	1.96	2.04	+4.1
Gender						
male	2.10	2.45	+16.7	2.00	1.79	-10.5
female	1.60	2.21#	+38.1	1.90	2.33	+22.6
Level of ID						
Mild ID	1.82	2.34#	+28.6	2.24	2.10	-6.3
Moderate ID	1.47	2.00	+36.1	1.44	1.94	+34.7
Living arrangement						
Independent living with support	1.83	2.43#	+32.8	1.89	2.33	+24.4
Living in an institution	2.00	2.71	+35.5	2.00	2.50	+25.0

matched t -test: p< .05

For women, persons with mild ID and persons living independently the increase in knowledge is statistically significant. Women gained more knowledge than men and persons with mild ID show a clear improvement in their knowledge on this subject. In the intervention group at T1 people living independently with support gained statistically significant in knowledge on health and well-being.

6.4.3 Fitness

The lessons on Fitness (Doing Exercise and Making other Healthy Choices) focus explicitly on doing daily exercises. Participants learn the importance of doing daily exercises and pick a simple program of daily exercises. Table 6.7 shows the results regarding knowledge of fitness. Both the intervention and reference groups show a lower mean score on all subgroups with the slight exception of persons living independently with support. Male persons in the reference group even show a statistically significant decrease in their knowledge about exercising daily and making healthy choices.

Table 6.7 Fitness (score 0 - 10): comparison of the mean score and change (%) between the intervention group (N=94) and reference group (N=45)

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	6.36	6.15	-3.3	6.86	6.0	-12.2
Gender						
male	6.35	6.32	-0.5	6.71	5.63[#]	-16.1
female	6.37	6.06	-4.9	7.05	6.50	-7.8
Level of ID						
Mild ID	6.32	6.19	-2.1	7.24	6.52	-9.9
Moderate ID	6.60	5.93	-10.2	6.13	5.07	-17.3
Living arrangements						
Independent living with support	6.57	6.76	+2.0	7.39	6.33	-14.3
Living in an institution	6.94	6.65	-3.6	8.67	7.67	-11.5

[#] matched t -test: p< .05

6.4.4 Leisure-time activities

Leisure-time activities are another important theme of the curriculum Later Life Planning. Participants are made aware of various activities one can pursue in one’s leisure-time and the importance of being active versus being inactive.

Table 6.8 Leisure-time activities (score 0-15): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45).

	Intervention group					
	Reference group					
	T0	T1	%	T0	T1	%
Total	7.16	7.36	+2.8	7.56	7.20	-4.8
Gender						
male	7.39	7.84	+6.1	7.04	6.75	-4.1
female	7.05	7.14	+1.3	8.14	7.71	-5.3
Level of ID						
Mild ID	7.04	7.57	+7.5	7.72	7.38	-4.4
Moderate ID	7.80	6.33	-18.8	7.25	6.88	-5.1
Living arrangements						
Independent living with support	7.26	8.45[#]	+16.4	7.06	7.67	+8.6
Living in an institution	8.00	7.59	-5.1	9.00	7.50	-16.7

[#] matched t -test: p< .05

Table 6.8 shows the results on Leisure-time activities. After the training participants had a lightly higher mean score on knowledge concerning leisure-time activities, while persons in the reference group showed a decline. The difference however is only small and statistically not significant. Taking a closer look at subgroup level, one sees that participants living independently gained significantly more knowledge than persons living inside an institution: the latter even seem to have lost knowledge that was present before the training!

Tables 6.9 and 6.10 give an overview of the top-ten leisure time activities of both the intervention and reference group at T0 and T1.

Table 6.9 Top ten of leisure time activities in the intervention group (n=91) at T1 and T2

T0		%	T1		%
1	Watching TV	96	1	Shopping for pleasure	98
2	Shopping for pleasure	93	2	Watching TV	96
3	Relaxing	90	3	Listening to music	94
4	Visiting family and friends	89	4	Visiting family and friends	94
5	Listening to music	88	5	Relaxing	92
6	Dating	84	6	Going to parties	88
7	Dining out	82	7	Dining out	86
8	Going to parties	82	8	Traveling	85
9	Traveling	78	9	Dating	86
10	Walking for pleasure	69	10	Doing exercise for pleasure	74

Table 6.10 Top ten of leisure time activities in the reference group (n=91) at T1 and T2

T0		%	T1		%
1	Watching TV	100	1	Watching TV	96
2	Shopping for pleasure	93	2	Shopping for pleasure	94
3	Listening to music	91	3	Dining out	93
4	Relaxing	91	4	Relaxing	91
5	Going to parties	85	5	Listening to music	89
6	Dining out	83	6	Going to parties	89
7	Visiting family and friends	83	7	Dating	87
8	Traveling	82	8	Traveling	87
9	Walking for pleasure	73	9	Visiting family and friends	85
10	Dating	74	10	Walking for pleasure	69

The tables do not show many differences between the two groups: at T0 all interviewees do engage in the same leisure time activities with watching TV as the number one activity. The only new item that pops up among the top ten items in the intervention group at T1 is “doing exercise for fun” at number ten: a topic highly promoted in the curriculum, and henceforth unknown to the reference group. At T1 in the intervention group it swapped places with “walking for pleasure”; for persons in the reference group “walking for pleasure” remains at number ten of favorite leisure time activities.

6.4.5. Work and Pension

In the part of the curriculum dealing with Work and Pension participants learn how - over the years - their work-pattern can change from full-time work to part-time work and eventually full retirement or pension. The various reasons are discussed why people might want to change from working full-time to working part-time and why some people eventually might want to stop working at all. At the end participants' individual possibilities and wishes for the future are discussed: why, for instance is it good to have work or to change the kind of work you do?

Table 6.11 Work and Pension (score 0-9): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45).

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	3.63	4.08	+12.4	4.82	3.82#	-20.7
Gender						
male	3.77	4.39	+16.4	4.63	3.50#	-24.4
female	3.56	3.92	+10.1	5.05	4.19	-17.0
Level of ID						
Mild ID	3.52	4.12#	+17.0	5.45	4.04#	-25.9
Moderate ID	4.20	3.87	-7.9	3.69	3.38	-8.4
Living arrangements						
Independent living with support	3.83	4.33	+13.1	5.17	4.11	-20.5
Living in an institution	3.94	4.24	+7.6	5.00	4.25	-15.0

matched t -test: p< .05

After the training participants showed a significant increase in knowledge of work and pensions compared to persons in the reference group. After a period of five months all persons in the reference group show a statistically significant decline of knowledge on this subject; more specifically, the decline is found in male persons and persons with mild ID.

6.4.6 Living arrangements

In these lessons participants are informed about the many possible living arrangements there are and about the pros and cons of each of them. Special attention is given to the various positive aspects of their present living situation, and to individual preferences in future living arrangements. Another point to be discussed here is how people can make positive changes in the house they live in and how they can improve their contacts with fellow room- or housemates.

Table 6.12 Living arrangements (score 0-4): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45).

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	2.13	2.30	+8.0	2.58	2.36	-8.5
Gender						
male	2.42	2.52	+4.1	2.42	2.25	-7.0
female	1.98	2.19	+10.6	2.76	2.48	-10.1
Level of ID						
Mild ID	2.05	2.29	+11.7	2.79	2.52	-9.7
Moderate ID	2.53	2.33	-7.9	2.19	2.06	-5.9
Living arrangements						
Independent living with support	2.24	2.62	+17.0	*2.50*	*2.67*	*+6.8*
Living in an institution	2.29	2.00	-12.7	*2.75*	*3.25*	*+18.2*

matched t -test: p< .05

The results of training “Living Arrangements” are shown in Table 6.12. In general, persons in the intervention group - with the exception of persons with moderate ID and persons living in institutions - gained more knowledge of living arrangements than persons in the reference group. All persons in the reference group - irrespective of the place they live in - showed an increase in knowledge on living arrangements at T1, but the difference between T0 and T1 is statistically not significant.

6.4.7 Individual Care Plan

In the last lesson of the curriculum participants learn how to state their goals and how they can prepare themselves for the Individual Care Plan Meeting. Together with trainer, co-trainer, a family member or an individual care person they formulate their goals thinking back of all the choices they made during the past lessons. These goals are written down in an Action Plan that also takes care of possible barriers one might encounter when pursuing a specific goal. This Individual Action Plan is supposed to be taken to the next Individual Care Plan Meeting to help the student formulate his future choices.

Knowledge about the Individual care Plan Meeting is assessed by two questions:
“During an Individual Care Plan Meeting, are you supposed to:
(2) Say what you want to happen for yourself? or
(0) Listen and let the staff do most of the talking?”

“What is a goal?”
(2) Something you want to happen for yourself? or
(0) A rule about how you are supposed to act?”

Looking at the results of the testing at T0 it became clear that from the 91 persons interviewed only 48 persons knew the answer to the first question - 43 persons missed the question. From the comments on the interview sheets it became clear that they either did not know what a Care Plan Meeting was or they were not supposed to attend the meeting. 49 persons answered the second question - 42 persons did not understand the question or gave a wrong answer.
So table 6.13 shows the answers of only 49 participants - the remaining persons gave invalid answers.

Table 6.13 Individual Care Plan (score 0 - 4): comparison of the mean score and change (%) between the intervention (N=49) and reference group (N=45)

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	0.89	1.15	+29.2	0.59	0.63	+6.8
Gender						
male	1.16	1.29	+11.2	0.76	0.57	-25.0
female	0.76	1.08	+42.1	0.35	0.71	+103.0
Level of ID						
Mild ID	0.81	1.22$^{\#}$	+50.6	0.64	0.64	0.0
Moderate ID	1.33	0.80	-39.8	0.46	0.62	+34.9
Living arrangements						
Independent living with support	1.03	1.26	+22.3	0.76	0.67	-11.8
Living in an institution	0.63	0.94	+49.2	0.35	0.59	+68.6

$^{\#}$ matched t -test: $p< .05$

The persons in the intervention group that gave valid answers to the questions at both T0 and T1 did learn more about Individual Care Plans than persons in the reference group; persons with mild ID have gained significantly more knowledge than those in the reference group.

6.5 The effects of the curriculum on satisfaction before and directly after the training

The second research question is:
What are the effects of the training on participants’ satisfaction with leisure time activities, living and work arrangements?

6.5.1 Satisfaction with leisure time activities

Results show that participants are more satisfied with their leisure time activities after finishing the training (Table 5.11). The difference is statistically significant. Within the intervention group men, persons with mild ID and person living independently with support are more satisfied with the activities they can pursue in their free time. On average, persons with moderate ID become less satisfied.

Table 6.14 Satisfaction with leisure time activities (score 0 - 4): comparison of the mean score and change (%) between the intervention (N=91) and reference group (N=45)

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	3.74	3.94[#]	+5.3	3.87	3.80	-1.8
Gender						
male	3.70	4.00[#]	+8.1	3.88	3.92	+1.0
female	3.77	3.91	+3.7	3.85	3.65	-5.2
Level of ID						
Mild ID	3.69	3.98[#]	+7.9	4.00	4.00	0.0
Moderate ID	4.00	3.76	-6.0	3.67	3.50	-4.6
Living arrangements						
Independent living with support	3.75	3.97[#]	+5.9	3.83	3.87	+1.4
Living in an institution	3.74	3.88	+3.7	3.91	3.73	-4.6

[#]matched t -test: p< .05

6.5.2 Number of leisure time activities

Participants were asked about the number of leisure time activities before and after the training (see table 6.14). In both intervention and reference groups the mean number of leisure time activities increased after the training; women in the intervention groups benefited most from the training with a greater number of activities available to them at T1.

6.5.3 Satisfaction with living arrangements

After the training persons in the intervention group prove to be less satisfied with their living arrangements (see Table 6.15) than they were before. This is in sharp contrast with the results of the reference group on T1 where people in general show little but increased satisfaction with their living arrangements.

Table 6.15 Number of leisure time activities (score 0 - 48): comparison of the mean score and change (%) between the intervention (n=84) and reference group (n=42).

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	20.68	21.15	+2.3	20.60	21.26	+3.2
Gender						
male	22.07	19.97	-9.5	20.67	21.50	+4.0
female	19.91	21.81#	+9.5	20.50	20.94	+2.1
Level of ID						
Mild ID	20.96	21.56	+2.9	22.21	23.00	+3.6
Moderate ID	19.29	19.14	-0.8	18.44	18.94	+2.7
Living arrangements						
Independent living with support	21.44	21.93	+2.3	21.64	22.55	+4.2
Living in an institution	19.24	19.69	+2.3	19.45	19.85	+2.1

#matched t -test: p< .05

For both research groups there is no statistical difference between T0 and T1 in satisfaction in living arrangements. Within the groups there are some remarkable differences though. After the training female participants are significantly less satisfied with their present living arrangement, as are persons with moderate ID living in institutions.

Table 6.16 Satisfaction with living arrangements (score 0 - 10): comparison of the mean score and change (%) between the intervention (N=89) and reference group (N=45)

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	9.93	9.33	-6.0	9.48	9.80	+3.4
Gender						
male	9.43	9.50	+0.7	9.42	9.96	+5.7
female	10.19	9.24#	-9.3	9.55	9.64	+0.9
Level of ID						
Mild ID	9.76	9.41	-3.6	9.52	9.67	+1.6
Moderate ID	10.86	8.86#	-18.4	9.42	10.0	+6.2
Living arrangements						
Independent living with support	9.72	9.60	-1.2	9.71	9.67	-0.4
Living in an institution	10.31	8.84#	-14.2	9.23	9.95	+7.8

#matched t -test: p< .05

6.5.4 Satisfaction with work

Because persons over 65 and other younger persons had already stopped working, the numbers in the intervention and reference groups dropped from (see Table 5.13).

After the training participants - especially persons with mild ID - were less satisfied with their working situation. As a whole, satisfaction with the working situation decreased in the intervention group, compared to the reference group.

Table 6.17 Satisfaction with work (score 0 - 10): comparison of the mean score and change (%) between the intervention (N=41) and reference group (N=21)

	Intervention group			Reference group		
	T0	T1	%	T0	T1	%
Total	8.49	7.37#	-13.2	7.62	7.19	-5.6
Gender						
male	8.00	7.30	-8.8	7.92	7.17	-9.5
female	8.65	7.39	-14.6	7.22	7.22	-
Level of ID						
Mild ID	8.16	7.35#	-9.9	7.69	7.31	-4.9
Moderate ID	9.50	7.40	-22.1	7.40	6.80	-8.1
Living arrangements						
Independent living with support	9.04	7.54	-16.6	7.79	6.93	-10.9
Living in an institution	7.31	7.00	-4.2	7.29	7.71	+5.8

#matched t -test: p< .05

6.6 Explaining underlying characteristics of older persons with ID

To explain which characteristics of older persons with ID caused the results on the domains of knowledge and satisfaction (dependent variables) multiple linear regression analyses was carried out. In this process the scores on all aspects of the knowledge and satisfaction scales at baseline (T0) were subtracted from the scores found right after the training was finished (T1), then the scores were summed up. This summation resulted in two independent variables gained “knowledge” and gained “satisfaction”.
To be able to find the underlying characteristics mentioned above some aspects of all persons participating in this study - intervention vs. reference group, gender, level of ID and living arrangement - were put as independent variables with the dependent variables “knowledge” and “satisfaction”.

Table 6.18 shows the results of the two regression models.

Table 6.18 Multiple regression analyses on aspects of “knowledge” and “satisfaction”

Independent variables / dependent variables	R^2	group		gender		level of ID		living arrangement	
		beta	p	beta	p	beta	p	beta	p
Knowledge	0.82	-.235	.01#	-.020	.83	-.056	.53	-.102	.25
Satisfaction	0.10	.040	.79	-.087	.55	.032	.82	.197	.84

R^2 explained variance
b standardized beta
p # significant

In explaining total gain of knowledge, being a member of the intervention group made a statistically significant contribution. The other included factors were less important. With an explained variance of R^2 = .82 the model is quite stable and exhaustive.

The regression model does not show a significant role for the variable “intervention group” on explaining gain of satisfaction. With an explained variance of $R^2 = .10$ it can be expected that other important variables are missing in the model.

6.7 Semi-long term effects of the curriculum

In order to be able to establish the semi-long term effects of the curriculum, the intervention group got a T2 interview in the autumn of 1998, three months after course end. It was not possible to include the reference group in T2 because in September - as promised - courses
had started with persons from the (former) reference group.

At T2 there were 88 persons in the intervention group, three persons less than at T1. One person was in the hospital and two others declined to have another interview. The same set of questionnaires was used at all three times and the change (positive or negative) in the knowledge on the same aspects - choice making, aging, fitness, leisure time activities, work and pension, living arrangements and Individual Care Plan - and satisfaction was studied.

6.7.1 Semi-long term effects on aspects of knowledge

The changes on aspects of knowledge are shown in Table 6.19. The main question is whether the knowledge is stable in the memory of participants three months after the end of the course. Changes in T1 - T0 show short-term changes (T1 was measured directly after the course was finished); changes in T2 - T0 show semi-long term effects.

Table 6.19 Changes on aspects of knowledge in the intervention group at T1 and T2

Aspect	mean T1 - T0	p	mean T2 - T0	p
Choice-making	.55	.036*	.65	.016*
Aging	.59	.002*	.40	.156
Fitness	.35	.130	.39	.108
Leisure time activities	.33	.488	.03	.946
Work and Pension	.38	.212	.09	.778
Living arrangements	.09	.659	- .03	.878

matched t -test: p< .05

As can be seen in Table 6.19 “choice-making” - the promoting of which is the red thread of this thesis - is the only aspect on which students consistently gained knowledge from base-line till three months after finishing the course. The increase in knowledge on choice making opportunities at T2 is again statistically significant; the increase is even more statistically significant than at T1.
The increase in knowledge on the concept of “aging” looked very promising at T1 - the increase being highly significant - but the gain in knowledge did not persist over time. At T2 participants still know more about the concept of aging than at T0, but the difference is no longer statistically significant.
There is a slight increase in knowledge on “fitness” at T2, but knowledge on “leisure time activities”, “work and pension” and “living arrangements” at T2 did decrease to the level of knowledge of participants as measured at baseline.

6.7.2 Semi-long term changes of Satisfaction

The changes in participants’ satisfaction is presented in Table 6.20. On group level the negative trend in satisfaction with living arrangements and in satisfaction with work and pension was still present at T2, three months after the last lesson, but the decrease between T0 and T2 was no longer statistically significant.

Table 6.20 Changes on aspects of Satisfaction in the intervention group at T1 and T2

Aspect	T1 - T0	p	T2 - T0	p
Leisure time activities	3.93-3.81 N=81	.181	3.86- 3.83 N=82	.552
Living arrangements	9.88-9.04 N=73	.052*	9.75-10.41 N=74	.138
Work and Pension	9.72-7.42 N=36	.64*	8.86- 8.54 N=35	.808

matched t -test: p< 1.0

Over time on group level participants also became less satisfied with their leisure time activities, but this decrease never was statistically significant.

6.8 Discussion

With all the reported positive effects of teaching the curriculum “Later Life Planning for Adults with Mental Retardation” in the US (see Chapter V), it was very challenging to see if a comparable group of older persons with ID in the Netherlands could also profit from the curriculum. This study was planned as a replication of the research done in the US. There were some differences though.
In the US extensive research was done on the goal setting process: two months after the course ended information was gathered on the specific goals participants did set in the last session. Ten months later again data were collected on whether these goals were met and what specific impediments participants experienced in trying to attain their goals. In the Netherlands this part of the study was not replicated.
In the Netherlands there was a third measurement three months after participants finished the course; this T3 measurement was not done in the US.

At T2 in the US a statistically significant increase was found in the mean curriculum knowledge score for the intervention group over the comparison group (see Heller et al., 2000). The significant items spanned the domains of health and well-being, recreation and leisure, work and retirement and living arrangements. As the research presented above shows, Dutch participants were also more knowledgeable after the course than they were before on the main six concepts - choice-making, aging, fitness, leisure time activities, work and pension and living arrangements -although this gain in knowledge could not be sustained over the three months period after the course ended.

The only - and most important exception - was the gain in knowledge on “choice-making”. The increase in knowledge was even larger and more statistically significant three months after the end of the course. Even at a longer range Dutch participants knew better what their options were.

Table 6.21 Choice making: comparison in percentages of the results of the intervention group (N=88) at three different times.

	Intervention group T0	T1	T2
Do you, or does somebody else, get to choose? "I do" says (%):			
- what food you eat?	71	77	72
- what clothes you wear?	88	95	89
- what things you do in your free time?	94	97	99
- what TV shows you watch?	95	99	97
- how you spend your money?	75	72	55
- when to go out with friends?	92	94	92
- what time you go to bed?	96	97	92
- how do decorate your room?	91	93	92
- when you clean your room?	69	60	52
- when you have guests visiting your room?	92	97	95
- what job you have or what work you do at your workplace	82	85	73

Looking at Table 6.21 one must say that participants' choice-making opportunities are already quite high at baseline so that an increase to make choices in their actual living environment might not be expected. Their knowledge on choice making did increase, however, but this increase was not paralleled in choice-making opportunities and actual decision-making in every day life. This finding underscores earlier research (Lakin et al., 1992; Wehmeyer & Metzler, 1995) that even if persons with ID learn about and practice choice making, they are likely to face the barrier of an environment that offers little opportunity to make use of their newly gained skills or only in areas that are not that important like picking your own free time activities and inviting friends to your room.

The important lesson to learn here is that support from the environment is essential: although much effort was given to preparing family members and individual care persons for the lessons participants were going to learn and the support that was asked from them, every day routines were stronger than even the best intentions. Family members and staff were easily run over by the demands of day to day care and - let's be fair - asking a person what he or she really wants takes time.

Table 6.22 shows the amount of choice making in the US and in the Netherlands. In both countries the number of choices made at T1 by the intervention group increased significantly over the number of choices the reference group made.

As can be seen from Table 6.22 there are various differences between the amount of choice between US participants and Dutch participants. Some difference may be explained by the percentage of persons with mild versus moderate ID. In the US study 52% of the sample had a moderate ID, in the Dutch sample 24%; in the US sample 48% had a mild ID, in the Dutch sample 76%. Another explanation may be found in the living arrangements between the two groups.

In the Dutch sample 43% lived independently; 19% lived independently with support and 38% lived in an institution. In the US sample 37% lived with their relatives; 32% lived in residential programs; 24% lived in independent or semi-independent programs; and 7% lived in foster homes (Heller et al., 2000). Although it may be difficult to compare the US and Dutch data on living arrangements, more Dutch participants lived independently and more Dutch participants had a mild versus a moderate IQ compared to the US population. This - apart from cultural differences - may be an explanation for the differences in amount of choices in the two outcomes.

Table 6.22 Percentage of Participants having Daily Choices by Country, Group and Time

	Intervention group				Reference group			
Choices	US (n=38)		Dutch (n=91)		US (n=22)		Dutch (n=45)	
	T1	T2	T1	T2	T1	T2	T1	T2
What food to eat	29	45	71	77	41	36	65	69
What clothes to wear	84	92	88	95	73	77	77	73
What things to do in your free time	82	90	94	97	77	82	94	95
What TV show to watch	68	79	95	99	96	91	91	91
How to spend your money	68	87	75	72	82	68	62	58
When to go out with friends	55	74	92	94	77	82	89	78
When to go to bed	84	95	96	97	91	86	83	76
When to decorate your room	56	87	91	93	73	68	89	73
When to clean your room	61	74	69	60	77	73	58	47
When to have guests	50	68	92	97	73	73	78	96
What job you do at workplace	21	50	82	85	62	50	63	52

In the US no significant main effect of life satisfaction over time was found nor any significant differences between intervention and reference groups, although the intervention group slightly increased in life satisfaction and the reference group slightly decreased; the differences not being significant (Heller et al., 2000).
In the Netherlands the picture is more complex: satisfaction in participants for leisure time activities increased significantly in time after the course, as did satisfaction with work. Satisfaction with living arrangements significantly decreased for female participants and participants with moderate ID living in institutions. This latter finding follows a rather consistent pattern: results found in the US (Sutton et al., 1994; Heller & Factor, 1996; Heller et al., 2000) and in Germany (Haveman et al., 1999) show the same results. The reason for this finding may be that participants living in an institution learning about the many other possible living arrangements become aware of their present living situation, which results in feelings of dissatisfaction.

As was already pointed out in the first evaluation of the curriculum (Heller et al., 1996) the curriculum is best suited for persons with a mild and a moderate ID. The course is too challenging for persons with a severe ID; they often lack the competence of planning over time and are only scarcely capable of reflection over things that happened in the past. That is why no persons with a severe ID were included in the Dutch study.

In the Netherlands the curriculum “Later Life Planning for Adults with Mental Retardation” is widely used - often adapted to the needs of the specific service that offers the training. Some services use parts of the curriculum - for instance about fitness, leisure time activities and making friends - for younger persons with ID.
Until 2004, five “train-the-trainer” courses were organized in which about fifty persons took part. A new “train-the-trainer” course will start in May 2005. It can therefore be concluded that the course is successful in the field of ID and fills the need to (better) prepare older persons with ID for later life.

In learning what it means to get older and how to influence their life through keeping good health, maintaining friends and planning their leisure time the curriculum offers excellent opportunities to age well. The course should therefore become an integral part of any service's program.

Chapter VII

Death, Dying and Loss - A Curriculum for Older Adults with Intellectual Disabilities

Introduction

In earlier days, individuals with ID were frequently kept away from death and loss experiences by well-intentioned care providers and family members (Dowling, 2000). Through the pioneering work of Maureen Oswin (1981, 1985, 2001) these ideas have been widely refuted. All people do experience some feelings when confronted with loss - death being the ultimate loss-experience - and people with ID respond to loss and bereavement in essentially the same way as anyone else. Recent research (Bonell-Pascual et al., 1999) has confirmed earlier findings (Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997) that for people with ID the effects of bereavement can be prolonged if not properly addressed resulting in people feeling more anxious, depressed and irritated.

Within a group of 43 adults with ID Harper and Wadsworth (1993) found irritability and hostility to be the two most common, very intense behaviors. Their care providers - mostly social workers, but also psychiatrists and psychologists - evaluated these behaviors as being dysfunctional and tried to curtail them with an increase in program structure and psychotropic medication thus preventing the persons involved from a proper working through of the grief process. Inappropriate “treatment” of quite natural responses to loss can make a difficult situation much worse (Bicknell, 1983).

In their study Hollins and Esterhuyzen (1997) compared 50 persons with ID, who were cared for in the community, and had recently lost a parent, with 50 others who had not been bereaved. The group that experienced personal loss was unlikely to have been warned of the coming death of their parent, they were not taken to the grave and only half attended the funeral. The bereaved persons had much higher scores on measures of anxiety, depression, hyperactivity, stereotyped movements and other indicators of distress than persons in the control group. Most importantly, despite all these “warning signals” most of the professional and family carers were quite unaware of their distress and were inclined to attribute their symptoms to brain damage (“diagnostic overshadowing”) rather than as consequences of their bereavement. Depression - albeit a situational depression (Harper & Wadsworth (1993) - is of specific importance in this respect. In the field of care for people with ID a lot of knowledge on psychiatric illness has “leaked away“ since institutions were closed and people started to live in the community. As a result depression is often not diagnosed as such. People look for all kind of explanations for the observed behavior - only not for depression. Depression - and other psychological symptoms - are often indicators that a person is becoming aware of the loss and time has come to acknowledge the need to grief. That is the time when family members and professional carers have to start to support that person through his or her grief (Hollins & Sireling, 1994; Luchterhand & Murphy, 1998; Meeusen-van de Kerkhof et al., 2001; Maaskant et al., 2002). It is important to help people with (and without) ID to express their feelings, to verbally rehearse possibly disturbing events surrounding the death of a loved one and to give an interpretation of the loss event.

In general, grieving people tend to oscillate between avoiding and confronting grief; problems arise when either of these ways of coping predominates. Therefore it is important to give people - especially persons with ID - “permission” and encouragement to grieve and to reassure them that grieving is a normal reaction (Parkes, 1998). They also have to be told that they do not have to grieve all the time - there may be time for relaxation and joy. It is therefore wise - more or less on a regular basis - to plan opportunities to talk about the loss so the mourning process can go on while pleasant daily routines do not have to be forsaken.

The time span a person grieves is highly individual and depends on a multitude of factors: the developmental level and age of the person, the particular experienced quality of the lost relationship, the frequency of grief experiences, the type of death (accidental or disease related), the existing social and environmental supports, spiritual or religious beliefs, prior general behavioral and emotional adjustment, and the person’s general anxiety about death and illness (Harper & Wadsworth, 1993). Cultural influences have a strong effect on when and how grief is expressed (Parkes & Markus, 1998). Anthropologists have reported great variation from one society to another, and even within cultures (Rosenblatt, 1993). Culture also prescribes when and whether grief is an appropriate response; the differences in the amount of crying granted to men - if at all - and women is shaped by the institutions and norms of the culture or social group one belongs to (Parkes et al., 1997; Doka & Davidson, 1998).

7.1 Grief responses

Grief responses in persons with ID can be categorized in four groups: emotional, physical, behavioral and psychological (Worden, 2001):

- emotional responses include: sadness and (separation) anxiety, anger and shock, aggression, guilt and self-reproach, loneliness and yearning, fatigue and numbness and sometimes also relief because there has come an end to insufferable pain;
- physical responses may be: a feeling of hollowness in the stomach or of tightness in chest and throat, breathlessness and muscle weakness, lack of energy, an over-sensitivity to noises and a retardation of psychomotor abilities;
- on a behavioral level one might see: sleep and appetite disturbances, absentmindedness and social withdrawal, crying and sighing, dreaming and searching, sometimes to the point of restless over-activity, and attention-getting and/ or compulsive behavior;
- in psychological perspective a grieving person might feel disbelief and confusion over the disappearance of the loved one; one wants to think a lot about the deceased, even if it interferes with things that have to be done; one has the sense that the dead person is still around or other hallucinations or one wants to be dead oneself or feels worthless. Sometimes a person takes on the characteristics of the person who died, such as the way he or she talked or held his or her head, or eating the food he or she enjoyed.

In general, grief can result from traumatic losses or from developmental losses associated with the aging process (Machin, 1998). One might call a loss traumatic

when it was not foreseen, like loss by death of a parent, a family member or a carer or loss as a result from separation or divorce. A mother might grieve over the loss of a potential child through miscarriage, stillbirth or abortion and parents may grieve over the birth of a Down syndrome baby, and not being the “normal” baby they hoped for.
Persons with and without ID might also grieve over losses that are associated with the aging process, like the loss of a job through retirement, or the loss of a preferred milieu by moving from the familiar house or neighborhood to a nursing home or residential care. Inevitably in later life one experiences losses of one’s friends, independence, routines, what used to be and finally one’s future (Read, 1999).

When a loved one dies, a person essentially has four mourning tasks to fulfill (Worden, 2001):

1. to accept the reality of the loss
2. to work through the pain of grief
3. to adjust to a life without the deceased
4. to emotionally relocate the deceased person and move on with one’s own life.

In earlier days people with ID were often not allowed to grieve properly, resulting in an inadequate or incomplete mourning. As a consequence one could often observe behaviors like a denial of the reality of the loved one’s death or departure, an idealization of the loved one, a decrease in self-esteem, and feelings of guilt.

Individual biographies may cause difficulties in mourning in some persons with ID (Parkes, 1998). They may have had an ambivalent or insecure attachment to the deceased person because they were sent off to an institution at a very early age. In their childhood they may have learned to fear other persons or things, or their parents may have been over-protective, resulting in a learned helplessness, which - in a loss situation - prevents them from being able to cope with that loss. On the other hand, their family may have been unwilling to help or totally absent, thereby teaching the person with ID not to trust anybody. Finally, the bereaved person may have had a dependent or an interdependent attachment to the deceased, both resulting in low self-esteem. There also may be a history of psychiatric disorder.

In recent years research has been carried out to explore the relationship between an individual’s conceptual ability (IQ and/ or Piagetian conceptual level) and his or her understanding of the four concepts of death (Derry, 1979; Cotton & Range, 1990; Wittkowski, 1990):

- inevitability, the understanding that all living things eventually die;
- finality, the understanding that all life functions cease with death;
- irreversibility, the knowledge that - once dead - a deceased person (or animal) cannot return to life, and;
- causality, knowledge of the causes of death.

The relationship between conceptual ability, understanding of death, and grief is a complicated one. It might be that experience - having attended a funeral, being told by other people about death and its consequences - is more crucial in the understanding of the concepts related to death and dying than the conceptual level in the person with ID per se (Arenhövel, 1998).

In a study encompassing 108 adults with ID ranging in age between 30 to 83 years with a mean IQ of 53 Kennedy (2000) sought to determine what adults with ID understood about death and what factors might have an impact on their level of understanding. The outcome of this study was meant to lead to clues on which a curriculum dealing with loss, death and dying could be built. Among other things she therefore looked into the effects of the following four factors:

- Piagetian level of cognitive development
- verbal comprehension knowledge
- social interference skill
- experience with death.

Results of the study indicated that adults with ID did have a fairly good understanding of what death means and tended to conceptualize death, as do normal children without ID (Kennedy, 2000). Piagetian level of cognitive development was not related to understanding death, though verbal comprehension knowledge was, but that in itself did not predict death understanding in persons with an IQ of 50 or over. Earlier findings by Arenhövel (1995) were confirmed in that the most significant predictor - even independent of IQ - was experience: participants who did experience the loss of a loved one, did talk with someone about death and dying and did participate in rituals surrounding death and dying had a better understanding of the concept of death. Another result of the study also congruent with the findings by Harper and Wadsworth (1993) is that supported exposure to death and grief does help people with ID to recognize the basic facts about the cycle of life and also does increase their ease in responding to the death of a loved one in a socially acceptable manner.

Behavior, especially in people with ID, is more indicative of a person’s true feelings than verbalizations. In order to be able to understand whether a person with ID - even with a severe ID - is grieving, it is essential to look for uncharacteristic behaviors or changes in that person’s behaviors such as verbal or physical aggression or extreme withdrawal. Special attention is also needed if:

- sleeping patterns have changed,
- the bereaved person sleeps more or less than normal,
- sleep is disturbed,
- eating habits have changed,
- the person is withdrawing from social activities,
- there is an increase in the number or severity of physical symptoms exhibited,
- and any personality characteristics have changed (Luchterhand & Murphy, 1998).

Even nowadays when most people in the field recognize the need of people with ID to be able to mourn and are quite willing to support them in working through the mourning tasks, grief often goes unrecognized. The obstacles in recognizing grief include the following (Parkes & Markus, 1998):

- Some people still assume that a person with ID cannot understand a loss or experience grief - thus the subject is never discussed.
- The tendency of carers to want to protect people with ID from the experience of loss - which is an essential part of life - hinders recognition and acknowledgement of feelings, thereby limiting provision of supports.
- The person may not be able to verbalize his or her grief - so the person is not comforted.

- The symptoms of grief may not look “typical” symptoms of grief - and go unrecognized.
- There may be a delayed onset of symptoms - behavioral difficulties months or years after the death of a loved one are not seen as being connected to that death.
- A decreased or altered expression of emotion: some people with ID have never learned to express their true feelings - think of people who have long lived in institutional settings, or people who have experienced unpleasant consequences when they did share emotions.
- A tendency to respond in a positive manner: especially older people with ID have learned to respond in a socially desirable way - never show negative or angry feelings.

Before planning for a social or a therapeutic intervention it is important to distinguish between behaviors that are “normal” for a grieving person and behaviors that are indicative of a serious depression. In the first case, comfort and support often will be effective. In the latter case it is important to bring in professional help from an experienced psychiatrist or specialized psychologist who can alleviate the suffering in making the right diagnosis and give proper psychotherapy and drug treatment.

Special precautions have to be taken when the last parent of a person with ID has died and the person still lives at home. In such instances there is often no other possibility than to move him or her to some form of residential care. This period - apart from everything else - is a bad time for changing one’s living arrangements. Not only did the person lose his or her last resort, the person he or she likely trusted most in the world, the person who likely knew and understood him or her, but now there is also the loss of a home and a familiar neighborhood (Hubert & Hollins, 2000). Their often relatively small social circle becomes even smaller and the future might look like a big, black, very frightening hole (Kloeppel & Hollins, 1989; Luchterhand & Murphy, 1998). These are very traumatic circumstances in which the person with ID needs all the support he or she can get and an assessment of skills - in order to ascertain his or her best-suited place to live - should be avoided at all costs (Hollins, 1995).
Therefore families should start early planning for future residences for their relatives with ID, preferably long before the parents start ailing and the problems associated with death and eventually loss of the parents become apparent (Hubert & Hollins, 2000). Anticipatory guidance must also focus on families and professional carers because they are instrumental in assisting bereaved persons in periods of separation and loss. Effective communication and listening skills are essential in providing suitable care and support (Read, 2002).

7.2 Death, Dying and Loss - as a curriculum in adult education for persons with intellectual disabilities

Because individuals with ID differ greatly with regard to their cognitive disabilities and personal experiences, there was a need to develop prevention and intervention programs that could prepare persons with ID for future losses and helping them to work through recent and past losses. As more and more persons with ID stay at home with their aging and eventually frail parents, and/or became “old” themselves, the need becomes ever more apparent for a comprehensive, integrated and professional curriculum that can prepare adults with ID for future losses and deaths in their families.

Apart from being an instrument to actually teach persons with ID about loss, death and dying adult education also provides ways and means to help persons with ID to learn to cope with past or present losses. In this respect an adult education curriculum can also have a therapeutic angle.

On the basis of former evidence cited (Harper & Wadsworth, 1993; Luchterhand & Murphy, 1998) a curriculum dealing with loss death and dying should include enough cognitive material to build an understanding of the concept of death and strategies for effective coping and rebuilding relations following the loss of a loved person.

In a curriculum on loss and mourning developed by Yanok & Beifus (1993) the following goals are stated:

- within their environment participants should learn to distinguish between things alive and things dead;
- participants should learn that all living things eventually die;
- participants should learn that death is permanent and irreversible;
- participants should learn about fatal accidents, terminal illnesses and natural causes of death;
- participants should learn the meaning of words like funeral, graveyard, bereavement and dying.

In the eight lessons of 50 minutes each, there was formal teaching as well as discussion among participants. Learning materials - alive and dead - were brought in from participants' homes; Life Line pictures were also used. During discussions people are encouraged to share their personal experiences, thoughts and feelings on death, dying and bereavement. Any person should be absolutely free to participate in the training and should be free to leave at any time he or she chooses to do so.

In an evaluation of bereavement groups for adults with ID in which the curriculum of Yanok and Beifus was used, Stoddart et al. (2002) found that - compared to baseline results - participants did show only little change in anxiety, and their understanding and knowledge of the death and bereavement process did not improve significantly either. There was however a significant improvement in symptoms of depression, particularly in persons with ID and mental health problems.

On the basis of extensive research, the research team at The Institute for Life-Span Development and Gerontology at The University of Akron of Akron, Ohio developed another training: “Person-Centered Planning for Later Life: Death and Dying - a Curriculum for Older Adults with Intellectual Disabilities” (Sterns et al., 1999).

The curriculum builds on the same concepts as the Person Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation (Sutton, Heller, Sterns et al., (1994) namely:

- life-span development and
- an ecological perspective on empowerment.

Crucial elements in both curriculums are the same (see Chapter III):

- choice making;
- learning from other group members in a safe environment;
- a group lead by a trainer and a co-trainer, the latter being familiar with participants' life histories and trusted by them;

- each participant should have a personal care person to which he or she can turn to in between sessions.

Taking the normalization principle as a guideline and considering that all people go through a similar cycle of life, in the first planning stage lessons on Death, Dying and Loss were supposed to become one of the main themes in the "Later Life Planning Curriculum for Older Persons with Mental Retardation", next to Choice Making, Living Arrangements, Physical Exercise, Work and Retirement, Leisure-time Activities and Friends (see Chapter IV). Working on this broad curriculum, however, the authors concluded that because of their rather complex and complicated nature the concepts underlying Death, Dying and Loss should be taught and discussed more thoroughly in a separate module. Besides that, not all persons fit to learn about how to plan for later life are also fit to learn more about death and dying. Families might oppose it out of the feeling that their family member should be protected from the subject (see Introduction) and for some other reasons not all participants might be up to attending a course with this subject either. Another difficulty the authors came across was how to address religion. In their Introduction to the American Curriculum the authors state the following:

> "The reader will notice that references to God and/or any specific religious practices are of a general nature. Keeping in mind that some participants may come from families that do not have a religious orientation, the authors made the conscious choice to create a curriculum geared toward what some may consider a more secular viewpoint. No treatment can adequately represent all the various religious or ethnic variations in death and dying. We appreciate to the importance of religious beliefs in death and dying, and we are sensitive to the diversity of the perspectives held by the students who participate in the curriculum. We do endorse and have attempted to incorporate a sense of spirituality as much as possible. It is left to the discretion of the instructor, depending on the context, to determine how much, or how little, religious and/or ethnic perspective should be incorporated." (Page VI; Sterns et al., 1999)

7.3 The curriculum "Person-Centered Planning for Later Life: Death and Dying - a Curriculum for Older Adults with Intellectual Disabilities"

Because it is often not possible for the teacher to know each participant's grief history, the teacher's manual suggests that a staff or support person should be present in the room where the course is given. In every day practice the co-trainer will often fulfill this role. He or she knows participants well, and will be able to recognize and respond to expressions of grief and/or unresolved grief issues in any of the participants.
It may be that the topics covered during the lesson trigger adverse grief reactions among participants. Although it is unlikely, a participant may experience an adverse grief reaction so severe that it warrants intervention. If this occurs, the participant should be referred to a grief counselor experienced with persons with ID.

As in the Later Life Planning Curriculum it is essential that a care person is assigned to each participant: he or she should be aware of the content of the course and during the week be able to be supportive to his or hers client's needs.

Every new lesson starts with the rehearsal of the major topics discussed in the previous lesson.

7.3.1 Lesson One: Understanding Death

The goals of Lesson One are:

- To increase participants understanding of the cycle of life by explaining topics such as the lifespan, aging and age-related changes, and death dying and loss. Objectives related to this goal are: a) being able to identify points along the lifespan, b) identify the current position in the lifespan and c) recognize that death, dying and loss can occur at any point during the lifespan.
- To define the four concepts of death so that each participant will be able to demonstrate an awareness and understanding about death.
- To increase participants awareness of the need to celebrate the important people, places, events and things in their lives.

After the introduction of trainer, co-trainer and participants - if necessary, most participants have lived or worked together for years - Lesson One starts with explaining the Lifespan line. Pictures of persons of different ages are presented and the participants are asked to place the pictures - a baby, a young child, a young couple, an older couple, and an old couple - on the right place on the Lifespan line, representing the Cycle of Life.

With the help of posters and pictures the four concepts of death (All Living Things Die, Dead Things Cannot Come Back to Life, Death is Final, and Causes of Death) are explained at great length and with many rehearsals, the main message being that death is a natural part of the life cycle.

Lesson One closes off with a "Celebrate Your Life" poster, personalized to the trainer. This poster contains images of the people, places, events, and things that are important to the instructor. The purpose of the poster is to increase participants' awareness of the need to celebrate the people, places, events, and things that are important to them in their lives.

7.3.2 Lesson Two: Grief

In Lesson Two issues related to loss, grief and mourning are discussed. Participants learn to recognize feelings, thoughts, and behaviors experienced whenever a loss occurs, regardless of the type of loss - death of a loved one or departure of a dear staff person to another job. Participants learn that feelings like sadness, anger and guilt are all part of grief. Pictures of sad and angry faces help to explain the rather abstract concepts connected with grief. Sadness - “I cried when my mother died and I felt like there was a stone lying on my stomach” - is a well known feeling, relatively easy to talk about, but anger - “why did mother die and leave me alone?” - or guilt - “mother died because I was mad at her” - are more difficult to discuss. Participants learn that is quite normal to have these feelings and thoughts, which it is good to talk about them, as it is also good to talk about their own behaviors that may have changed after a loved one died.

7.3.3 Lesson Three: Mourning, Comfort and Support

In Lesson Three participants learn to understand the process of mourning, how to comfort and support others who have experienced a loss, and to whom they can turn to when they loose a person to death or when a major care person in their lives moves away.

With the help of posters and pictures participants learn that mourning is a difficult process in which one has to realize that the death or loss of the loved one really happened which in its turn causes deep pain and sadness. In order to go on with one's life one has to learn to cope with these feelings, one has to get used to the fact that losses are part of life, and to help the coping process one might engage in new things or make new friends. These are the so-called four mourning tasks. Participants also learn how to show comfort and support to bereaved persons: to share their feelings, to listen to their stories and to offer them sympathy, either by writing a card or a letter. The writing of a letter is extensively shown, as is -in a role-play - how to offer sympathy to a person who has lost a loved one.

7.3.4 Lesson Four: Death-Related Rituals - Visitations

Lesson Four provides the participants with knowledge and information about visitations either at a funeral home or at the house where the deceased person lived. Pictures are used to help explain the purpose of visitations (calling hours, wakes, sitting Shiva, mourning period) as well as what happens during a visitation and how one should behave, for instance signing a guest attendance book and saying good-bye to the deceased person. Participants also learn how to share and express grief, how to show sympathy and how to give condolences to the bereaved. At a visitation one can meet old acquaintances and make new friends. Some extra attention is given to the need to be dressed properly, with combed hair and clean hands.

7.3.5 Lesson Five: Death-Related Rituals - Funerals

In Lesson Five participants learn about funerals; what funerals are, the purpose of funerals and the choices available when planning a funeral, for instance what music could be played Participants are also told how to behave and give sympathy and condolences to the dead person's family when attending or participating in funerals. The lesson closes off with the Planning Choices and Family Considerations Game aimed at helping participants to make choices in relation to their own death.

7.3.6 Field Trip

The last part of the curriculum is a field trip to a funeral home. In cooperation with a leading person of a local funeral home, participants can be taken on a guided tour of the facility. The idea is to provide adult persons with ID with first-hand education about funerals and the opportunity to experience an aspect of the rituals surrounding death in a relatively non-threatening manner.

7.4 Evaluation of the US-curriculum

This curriculum was tested at five day-workshops in Summit County (Ohio). Participants were forty-one men and women aged 50 or older with mild to severe mental retardation, except for those with Down syndrome who were 35 or older. They were tested before (pre-test) and after the training (post-test) to find out if the training increased their understanding of death, dying, and loss. The testing and training took between 6-8 weeks.

For pre- and post-tests two instruments were used. Instrument one was a questionnaire with fourteen items that measured the main issues pertaining to the

curriculum. Instrument two was the Derry Death Concept Scale (Derry, 1979). Both instruments of the pre-test and post-test examined individual's understanding of the four death concepts - irreversibility, inevitability, finality, and causality. Pre- and post-tests were administered prior to teaching the curriculum and again approximately one week after the final field trip to a funeral home.
Individual questions from the pre- and post-tests were analyzed to determine if the number of individuals who understood the four concepts increased.

In the pre-test situations participants fairly well understood two out of the four concepts, namely finality and irreversibility; 78 percent understood the concept of finality and 75 percent understood the concept of irreversibility. After the training the scores on both tests increased to 89 percent, the conclusion being that participants were able to retain the lessons learned.
In the pre-test situation participants showed a poor understanding of the other two concepts: only 40 percent understood the concept of inevitability and 46 percent knew about the causes of death. After the training both figures rose to 89 and 65 percent respectively. These positive results clearly indicate that the training was effective in teaching the participants the four death concepts.
The conclusion of this pilot testing is that the Death and Dying curriculum is effective in teaching adult persons with ID issues related to death, dying, and loss and that participants are able to learn and retain the information presented in the training.

While training and researching the curriculum “Later Life Planning for Adults with Mental Retardation” in the Netherlands, our research group was often asked why the curriculum did not include a module on death and dying as so many persons with ID were confronted with death from housemates or family members and they, staff persons, did not have an appropriate answer to the distress death and loss caused in their clients.
Learning the tempting and positive results of pilot testing the Death and Dying Curriculum in the US, our group was curious to find out whether this curriculum would have the same positive results in the Netherlands. There were of course the cultural differences between the two countries, and there would be another sampling frame. In replicating the US study the question was if we would find consistency of results or would the outcomes be quite different. The other question was if it would be necessary to adapt the curriculum. All these questions and considerations lead to the evaluation study presented in this chapter.

7.5 Experiences with the Dutch course “Learning to cope with Death, Dying and Loss”

The first Dutch curriculum was a direct translation (van Laake et al., 2000) of the American text. Teaching the course in the Netherlands however, it soon became apparent that for future use adaptations had to be made, not only because of the - already presumed - cultural differences between the two countries, but also because pre-test results indicated that Dutch participants were far more knowledgeable on the subject of death and dying than the American participants. The main structure and content of the curriculum, however, remained very much the same.
A short description of the experiences of the teacher (Maria van Laake) with the curriculum and some of the changes that were introduced will be presented, as the individual lessons will be discussed below.

In the original American curriculum the finishing part of Lesson One is the presentation and discussion of the poster “This is your Life”, meaning the teacher’s life. In order to increase the awareness of the need to celebrate the important people, places, events and things in the lives of the participants, it seemed more reasonable to the Dutch teacher to have participants make - as homework - their own poster “This is your Life” and discuss each and everyone’s poster at the beginning of Lesson Two. It is not very helpful to discuss the highlights of the teacher’s life - graduation, marriage, getting your first child - with people who often cannot read or write, are not married and do not have a child. One of the bitter sours of their life might just be that - having no husband or wife and no kid to care for. Besides that, as was shown in Chapter IV, persons with ID learn the most from each other. To paraphrase L.P. Hartley (1953): “The life of the teacher is a foreign country: they do things differently there.”

Lesson Two starts with a discussion of participant’s Posters “This is your life”. In most instances the co-teacher did a great job in making photocopies of old pictures highlighting the events in participants’ lives: a trip to a cousin in Canada, the old family home, First Communion, the visit to Disneyland in Paris and being Prince Carnival. A very impressive poster was the one made by John with tens of pictures of John Deer tractors: John worked on the farm with a big John Deer machine, the most important thing in his life!

The discussion of all these private pictures also gives lots of clues to personalize future lessons: what is his or hers family background, where did the person grow up, what are his or her hobbies and so on. One should never forget that - how smart participants may sometimes look - they are all people with ID and their attention span is short and lessons have to be concrete and personal. Otherwise you “loose” your pupils and the teaching will have no effect.

In order to make things easier (or less threatening) to talk about, the teacher can discuss the feelings associated with death and loss - sadness, anger, guilt - in relation to the departure of a beloved carer who has taken a job elsewhere instead of the death of a parent or another loved one. Participants may have cried when their care person went away to another city, they may have felt really upset or they may have thought that he or she went away because they behaved so badly. All these rather disturbing feelings can be discussed in the safe knowledge that the care person is still alive and one could send a postcard saying that he or she is still in your heart and you think of him or her regularly. Having this in mind the teacher asked - as the homework for Lesson Two - participants to write, draw or paste a postcard and send it off to their beloved carer.

Dutch participants were quite aware of the issues surrounding death and bereavement, so several adjustments were made to the American curriculum. In stead of role playing behavior they already knew, participants were given the opportunity to tell what had happened when their parents or a housemate did die and what their role was in the proceedings. Participants were encouraged to tell about the funeral service or the cremation and about what happened afterwards, could they comfort the bereaved family and were there coffee and cake at the crematorium? Almost all of the participants had experiences in these respect and that’s why - in order to remain interesting and inviting - Lessons Three and Four of the American curriculum were molded into one Lesson Three in the Dutch course.

In Lesson Four - the last lesson in the Dutch curriculum - participants were able to discuss at length their own choices regarding the rituals surrounding death and dying like having a mass in church or a service at the cremation center, to be buried or to be cremated, the music and readings in the church or crematorium, the place of burial, and so on. Their wishes are written down by the co-teacher and kept in their dossier so that - when that person dies - family members and other caregivers know what to do.

Because of their Catholic orientation for the field trip the participants choose to go to a beautiful little chapel where since the Middle Ages people went to pray to the Virgin Mary for a good health and recovery from all kinds of ailments. They burned little candles in commemoration of their deceased family members and friends and prayed a little prayer. Afterwards there was coffee and a light lunch, a very rewarding closure of an intriguing learning experience.

In conclusion: the curriculum was adapted to participants' better understanding of the concepts and ceremonies surrounding death and dying. In order to keep the meetings attractive and rewarding, lessons were made more personal, for instance discussing participants' This is Your Life Poster in stead of the teacher's, and focusing on their ideas and wishes concerning memorial services, obituary's and eulogy's. The curriculum “Later Life Planning for Adults with Mental Retardation” does build on the same principles, namely to learn - or help - persons with ID to make their own choices. At the end of the last lesson the co-teacher wrote all participants' choices down and made sure this paper became part of the participant's dossier so, when people would come to their life's end, their carers would know about their last wishes.

7.6 Evaluation of the Dutch version of the curriculum

7.6.1 Sampling procedures, participants and organizational issues

Because of the sensitivity of the subject one had to be very careful in selecting the participants for the various groups. The best way to get into contact with possible students was to address the co-trainers that participated in training the curriculum “Later-Life Planning for Adults with Mental Retardation”. Not all former co-trainers could oblige to the request, but they were very willing to name colleagues who were familiar with older persons who - maybe - would be interested in attending a course on loss, death and dying either because somebody they knew had recently died or because of a fire in the institution just a few months back in which patients had died. Although staff could have stimulated some persons to participate in the course, at the end it was each person's individual choice - on the basis of informed consent - to subscribe to the course. This is an essential principle, because the curriculum is neither training nor therapy, but part of an adult education program of a person's own choice.

All possible candidates (Appendix IV) - or their legal representatives (Appendix V) - gave their informed consent on the participation in the curriculum and in the pre- and post-testing; they also agreed on the use of the collected data by the Maastricht University. Anybody who wanted to do so was free to leave the course at any time. At the end there were five groups of participants - two groups with seven students, one group with six students and two groups with five students. All participants lived in the Dutch province Limburg. Because it took so much time and effort to actually find students for the curriculum, the search for a control group was discarded.

Table 7.1 A description of the intervention group (n=30) on 5 characteristics

	Absolute	%
Gender		
- male	16	53%
- female	14	47%
Age (in years)		
40 - 49	6	20%
50 - 59	7	23%
60 - 69	13	43%
70 - 79	2	7%
80 -89	2	7%
Level of ID		
- light (IQ: 70-90)	10	33%
- mild (IQ: 50-69	20	67%
Living arrangement		
- group-home	12	40%
- socio-home	11	37%
- supported living	3	10%
- living with family	3	10%
- independent living	1	3%

The number of men and women participating in this adult education curriculum was almost equal (Table 7.1). The mean age of the participants was 61 years, with a range from 40 till 82 years. With a mean age of 65.3 years the women were significantly older than the men, whose mean age was 57.0 years. Two thirds of the persons had a mild ID; one third had a light degree of ID. Most participants lived in group-homes on the premises of institutions or in socio-homes in the wider community, three persons lived in supported living arrangements, three persons lived with their family and one person lived independently. During the six-week period of the course nobody missed a lesson because of illness or lack of interest - and nobody quit.

The teacher in all five courses was the same person (Maria van Laake); the co-teachers were persons familiar to and with the participants. One group was formed out of (older) visitors of a Day Activity Center, one group were persons that had the same case manager and the other three groups lived together in the same socio-home or group-home.
At the Day Activity Center the course took place in the afternoon. All other group sessions were in the evening, because people had to work during the day. The lessons were either given in the shared group-room or in meeting rooms on the premises. Each course consisted of five lessons, with one two-hour lesson each week and the field trip.

The curriculum was sequentially taught to the five groups and took place in the last four months of the year 2000 and the first six months of 2001. Speaking about death and dying: the concluding meeting of the last course was held on September 11th 2001!

7.6.2 Measures of knowledge and understanding of death

In order to be able to establish whether participants' knowledge on death, dying, and loss had increased after the training and whether participants did better understand the concepts of death, dying and loss, the questionnaire "Knowledge and Understanding of Death, Dying and Loss" (see Appendix VI) was administered before (T0) and directly after the course (T1). The first group started in September 2000 and the last one ended in June 2001.

Before the curriculum started participants (or their legal representatives) gave their written informed consent; all service facilities agreed both to the goal of the curriculum and to the participation of their clients in the research.
To ensure that the results can be compared with those of the American study, the same measurement instruments were used. To be more specific: the questionnaire that was used consists of a nineteen items pertaining to the content of the curriculum. The questionnaire was specifically developed for the Dutch assessments by van Laake, Reijnders and Haveman (July 2000) and is a combination of questions from the "Experience with Death Questionnaire" (Kennedy, 2000) and the Derry Death Concept Scale (Derry, 1979).

The trainer did the baseline test (T0) immediately before the groups started. In this way an opportunity was created to get to know the future students and possibly touch upon some sensitivities. An assistant did the post-intervention assessment (T1) within a week after the last group-session. In one socio-home both pre and post interviews took place in the room of the participants - the sessions were in the living room. In the other four groups participants were taught in small conference-rooms and interviewed in staff rooms belonging to the facility.

During the course no delayed grief responses in participants were found, although it may still be possible that some persons may develop problems in the future that deserve therapeutic attention.

7.6.3 Results

In order to establish a baseline assessment about participants' knowledge concerning death, dying and loss, the above-mentioned questionnaire was used (van Laake et al., 2000). From the first questions asked it was obvious that the interviewees knew what the concept of death meant: on many occasions in their lives they were confronted with the death of relatives, friends, coworkers or housemates. They described death and dying in concrete terms without mystifications or misconceptions (Good & Lynch, 2002).
As can be seen from Table 7.2 already in the pre-test situation nearly all participants had almost complete knowledge of what finality, inevitability and irreversibility of death meant; only on the item "causes of death" the trainer could teach anything new.

Participants were not quite aware of the many causes of death. They often replied, "I don't know." When asked:

1. What happens to a person's body if he or she dies? (Explanation: the heart stops beating, you stop breathing, your organs stop to work etc.)
2. What are the causes of death? (Explanation: old age, illnesses, accidents).

Table 7.2 Knowledge of the four basic concepts of Death and Dying (n=30)

	T0	T1
Concept 1: finality	95%	95%
Concept 2: inevitability	98%	98%
Concept 3: irreversibility	94%	94%
Concept 4: causes of death	48%	68%

Later on, during the group sessions, discussion - of what disease did your mother/ father/ aunt/ uncle/ grandfather/ grandmother died of? - helped to enlighten them in this respect.

Research mentioned earlier in this chapter (Kennedy, 2000) indicates that one of the best predictors of understanding loss, death and dying - as expressed in the above four basic concepts - is the individual's actual experience with loss, death and dying. Most people participating in the curriculum - all but the seven persons from the Day Activity Center and five persons from the case manager group - have lived in residential care for the most of their lives where they have witnessed other people die. Of all participants - except for one - the parents had died. Others mentioned the death of brothers or sisters or more remote family members or friends. So all participants at least witnessed the death of someone he or she knew. Group leaders mentioned that in many group-homes it was custom to hold small, private remembrance services when one of the group members died and often there were pictures of the diseased person on the TV-set or on the wall of the group room. All persons had been to a Mass or a funeral service and all had attended the condolence meetings afterward. Some visited regularly the graves of their parents or friends. In conclusion participants in this curriculum were very knowledgeable about death being the end of all living things, death is inevitable and no dead person ever comes back.
The only thing students still could learn about was the many causes of death: it may be that they did attend funeral services, but were not always aware of - or were told about - the actual cause of death of the beloved one. Table 5.2. shows a relevant twenty percent increase in knowledge in this field.

7.7 Discussion

Because of cultural differences between the U.S. and the Netherlands - among which the extensive saying-good-bye ceremonies in funeral homes and the importance of eulogies, which are fairly uncommon here - and the fact that the Dutch group apparently was much more knowledgeable than the original American group, the Dutch version of the curriculum was shortened to four lessons and a field trip. The last lesson is almost all dedicated to investigating the wishes of participants for their own funeral or cremation, the music they want to play, the place they want to be buried and so on. The structure of this last lesson is kept flexible in order to enable the trainer to fill in more details or give more extended information to accommodate each participant.
The core of the curriculum, however, remained unchanged: teaching older people with ID about death, dying and loss, its consequences in terms of emotions, thoughts and behaviors, how to cope with the disappearance of a loved one out of your life, and how to show support and comfort to other people who are bereaved.

A very important part of the curriculum is the opportunity it offers to participants to talk about their own feelings regarding the death of their parent(s) or siblings, the departure of loved professional carers, and their wishes concerning their own funeral or cremation. As research earlier mentioned shows, older people with ID often lacked the possibilities to mourn properly and many were never asked how they did image their own funeral or cremation.

In contrast to the findings from the general literature most participants in the Dutch course have witnessed the death of a loved one or a housemate and they were certainly not kept away from it. Sometimes this death was traumatic: in one group a caretaker committed suicide and in another group participants were very much involved in the death of a resident through fire, but staff gave ample opportunity to talk about feelings and mourn together. Everyone reported to have been very upset when their parents died and all have been to their parents' funeral. Next to a place where dead people are buried several participants also mention as a function of cemeteries to be able to visit the grave and thereby remembering their loved one. When asked almost all participants admit not to be afraid of dying - although one does not want to think of it too often and hopes to live for many, many years to come.

Although Dutch participants proved to understand the basic concepts of loss, death and dying well, this curriculum proved to be of great help in preparing (older) persons with ID for their own death and to help them to cope with past losses. In a short conclusive talk at the end of the last lesson, all participants indicated that the lessons had helped them talking about 'difficult' things - things that made them often cry. In the lessons they could talk about what was on their mind regarding the loss of loved one's and they need not to worry about their own future now with all things about their own funeral carefully written down in the last lesson. Participants said they also loved making the poster "This is your Life" - many had the poster pasted on his or her bedroom wall.

In exit-interviews co-trainers indicated that the curriculum was of great help in structuring talking about death and dying and they specially mentioned the non-threatening way in which the lessons touched upon sensitive subjects. They also warned about making this curriculum a part of the curriculum on Later-Life Planning. In their opinion one had to be careful to select the participants in the group and a person who was interested in getting new ideas to structure his or her leisure time or making new friends was not necessarily in the mood for a curriculum on death and dying.

Many co-trainers said that the curriculum would become a part of a plan for "End of Life Care" that their services were planning to organize for their older clients. On the trainer's question if this curriculum would also be usable for young persons with ID most co-trainers answered that it would be very apt to use the curriculum when loss, death or dying became concrete - when somebody in the family was very sick or when somebody they knew had died because of an accident. They advised against starting the curriculum for young persons with ID without a concrete reason to do so.

As the aim of the research in the Netherlands was to replicate the research done in the US, it is worthwhile to look for resemblances and differences between the found results regarding the four concepts of death. A close comparison yields the following

interesting observations. As was told above, on the pre-test, 78% of the US participants (n=41) answered the questions about the concept of the finality of death correctly. On the posttest, the score rose to 89%. In the Dutch sample (n=30) there was no difference in pre- and posttest scores: both were at 95%.
In the US sample, the same improvement can be seen on the concept of the irreversibility of death: a pretest score of 75% and a posttest score of 89%. Dutch participants had a 94% score on both tests.

Table 7.3 Knowledge of the four basic concepts of Death and Dying in the Dutch (N=30) and US sample (N=41).

	T0		T1	
	Dutch	US	Dutch	US
Concept 1: finality	95%	78%	95%	89%
Concept 2: inevitability	98%	40%	98%	98%
Concept 3: irreversibility	94%	75%	94%	89%
Concept 4: causes of death	48%	46%	68%	65%

On the two other concepts of inevitability and causality in the pre-test interviews the US participants showed a poorer understanding: 40% correctly answered the questions pertaining to the concept of inevitability and 46% to the causes of death. The scores in the Dutch group were 98% and 48% respectively. After participating in the curriculum 89% of the US group answered the questions correctly on the concept of inevitability and 65% could name more causes of death. Dutch participants were very much aware of what the concept of irreversibility means: on both pre- and posttest interviews 98% gave the correct answers.

The most interesting scores can be found on what both Dutch and US participants knew about the causes of death: on both pre- and posttest the percentages of correct answers are almost the same in both samples, 48% and 46% on the pretest and 68% and 65% on the posttest.

Although many efforts were made to ascertain the US demographic data, they could not be retrieved. The only thing that is known that the 41 participants were both men and women aged 50 years or older with mild to severe ID, except for persons with Down syndrome who were 35 years or older.
As can be seen from the Dutch demographic data, only persons with mild and light ID participated. So it may be that the higher intelligence level of the Dutch participants caused the high pretest scores on three out of the four concepts. It may also be that death and dying is more discussed or more a part of everyday life of the Dutch group, in other words: the reason for the found differences may be cultural. But because the data are not available the only thing that is left is to guess about possible reasons that explain the differences in outcome.

In general, on the basis of the experience with this curriculum one can say that Dutch (older) persons with ID were quite capable of expressing their feelings regarding death and dying of other people and that they did not feel constraint in talking freely about the hopes and expectations surrounding their own death. Perhaps family members and professional carers are more anxious in expressing their feelings in this respect than persons with ID, the latter often having a very down-to-earth kind of look at things that they feel are inevitable parts of the cycle of life. It may be that family and carers alike fear most the fear they fear.

Chapter VIII

The curriculum “Later Life Planning for Persons with Chronic Mental Health Problems”

Introduction

After the successful training of older persons with ID with the Curriculum “Later Life Planning for Adults with Mental Retardation” both in the US and the Netherlands (see Chapters V and VI) it seemed feasible to try out the curriculum with older persons who have chronic mental health problems (CMHP).
To put the outcome of this adult education curriculum into perspective, first an outlook will be given on the present day situation of persons with chronic mental health problems in the Netherlands, followed by some research findings on psycho-educational and cognitive training programs designed for persons with CMHP. In the second part of this chapter the training, method and results of teaching the curriculum “Later Life Planning for Persons with Chronic Mental Health Problems” are presented.

8.1 Persons with chronic mental health problems

8.1.1 The de-institutionalization movement in the Netherlands

As was explained earlier in Chapter III the de-institutionalization movement - that may also be called a de-hospitalization movement (Haveman, 1986) - got great impetus when in 1969 Nirje published his manifesto on the need to break down the big institutions and bring the inhabitants back to the community from which they originated (Nirje, 1985, 1992). Before him the anti-psychiatric movement with proponents like Goffman (1961) in the U.S., R.D. Laing (1965) in Great Britain and Jan Foudraine (1971) with “Wie is van hout ...” in the Netherlands forced people - both in and outside the medical profession - to rethink the reasons for putting psychiatric patients away from society in mental hospitals that had huge numbers of inmates and were often located in rural areas far away from where “real life was and normal people lived” (Nirje, 1969).

In the mid-seventies Dutch government started to make laws that enabled a shift in the care for psychiatric patients away from the big institutions, that, in 1975, had a mean number of 727 inmates to a maximum of 1,100 (Haveman, 1986), to more agreeable, smaller clinics and other small-scaled facilities, away from the moors and the dunes back to the cities, closer to families and friends. Another important step in the Dutch restructuring of care for the mental patients was the reallocation of money from clinical care to more ambulatory care and day-care, the so-called “substitution of beds” (Dekker, 1983). This shift in policy asked for “a continuity of care”, which means an optimization of the coordination between clinical, semi-clinical and ambulatory services and the building of more sheltered or halfway homes in the community.
The early successes in the US, the UK and Italy concerning deinstitutionalization (Haveman, 1982) could not be so easily repeated in the Netherlands (Haveman, 1986, 1989), where clinical care remained important, although from their start in the early 1980s the newly formed RIAGG’s (Regional Ambulatory Mental Health Care

Services) did a good job in providing ambulatory care for this growing group of clients.

From their beginnings in the late nineteenth and early twentieth century mental hospitals in the Netherlands have always accommodated two groups of persons that we now tend to see greatly apart: persons with a mental illness and persons with a mental retardation (Haveman, 1981).
Data from the Dutch National Case Register for Psychiatric Hospitals show a gradual decline in the number of the so-called “long-stay” patients (Haveman, 1989), partly because they died of old age and partly because in the mid 1980’s a large group of clearly mentally retarded persons left the psychiatric hospitals and moved into more appropriate settings belonging to the domain of services for persons with ID. During the last years there has been a tendency to discharge the younger patients as soon as possible (Haveman, 1989) which leaves behind a group of older and aging patients. Within this group of older, chronic patients is a residue of persons who came to the hospital when they were young and at the time were both mentally ill and mentally retarded with the serious mental illness overshadowing the mild mental retardation. In the scientific literature these persons are often named “persons with a dual diagnosis”. They often have had little or no chance to express their true wishes or to experiment with choice making. Over the last years there is ever more pressure, both from the Dutch government and from patient and family organizations alike, to move ahead on the path of deinstitutionalization and normalization: it is important to empower these people and give them a chance to live - according to their ability and to their choice - more independently within the community or, when that is not possible, to give them at least the opportunity to enjoy a greater choice in shaping their leisure time activities.

8.1.2 Characteristics of persons with a dual diagnosis

Although there are clear indications that the prevalence of mental health problems in persons with ID is high, the various definitions that are used to describe this population in various studies produce highly different outcomes. In their research Haveman et al. (1994) show that the level of ID and the etiology (Down syndrome vs. non-Down syndrome) of ID have a strong and systematic influence on the diagnosed prevalence. They found that twenty-five percent of the persons with mild ID living in institutions for people with ID were diagnosed with psychiatric problems, and 37.2% of the persons with severe ID. Most psychiatrists (Petry, 1995; Dosen, 1995) involved in the care for persons with a dual diagnosis agree upon the fact that all psychiatric symptoms that are present within the general population are also present in persons with ID. But there is strong evidence that the symptomatology as well as the clinical picture of a manic-depressive psychosis or schizophrenia in persons with ID show peculiarities that cannot be found in “normal” psychiatric patients. One seldom sees “the classic clinical picture”; in persons with ID the “picture” is more fragmented and highly depends upon the developmental level of the person involved. An observation corroborated by recent research by Stavrakaki (1999), who found that depression, anxiety and adjustment disorders are frequent among persons with ID and - in higher functioning individuals - very much follow the symptomatology as can be found in the general population. In persons with profound to severe ID however, the symptoms may overlap and include behavioral disturbances like aggression, irritability and self-injurious behavior.

The psychiatrist Detlef Petry (1995) estimates that from the 15.000 residential patients in Dutch mental hospitals - “the people that were left behind”, as he calls them - about one thousand persons also have a (mild) intellectual disability. Because of the nature of their psychiatric illnesses - long-term psychosis, chronic depression and brain organic processes (Toresini, 1983) - they have little chance leaving the hospital (Derks et al., 1995; van Laake et al., 1995; van Laake, 1999). Petry calls them highly vulnerable persons both in a psychological and social respect. They can be characterized by a clear discrepancy between what they want and what they actually can do; they do not have a clear perspective on things and they do not see connections between things. Hence, Petry claims, their being a full member of society is problematic, if not impossible. Patients deeply feel this discrepancy between their wishes and their capabilities, and therefore have great anxiety for their future. The understanding that they - probably - will not marry, have kids and live like “normal persons”, and that they will have to rely upon other people for the fulfillment of their present and future needs causes great pain and distress (Derks & Bernard, 1995).

8.1.3 Training programs for persons with chronic mental health problems (CMHP)

There are no specific adult education programs available today to prepare older persons with a dual diagnosis for problems they may confront when aging. For persons with “only” mental health problems there are several training programs, though, like cognitive and psychosocial training for schizophrenic patients. The psychosocial interventions herein used may include techniques like social skills training, psychoeducation, vocational rehabilitation, and psychotherapy. Anti-psychotic drugs are often prescribed to support these techniques and there is evidence that these drugs do improve cognitive functioning (Harvey & Keefe, 2001), but they do not eliminate all cognitive deficits (Rund and Borg, 1999) In his last Report on Mental Health (Department of Health and Human Services, 1999) the Surgeon General of the US advocates the combination of pharmacological and psychosocial interventions for an increased treatment benefit for patients with schizophrenia. One should be careful, however, in prolonged use of neuroleptic drugs; over time they can cause serious cognitive problems, like disorientation, memory loss and slowness of speech.

In a review article Twamley et al., (2003) provide information on seventeen published, randomized, and controlled studies of cognitive training interventions that were aimed at improving the neuropsychological functioning of persons with the diagnosis schizophrenia. Contrary to cognitive therapy, which focuses on modification of maladaptive beliefs, cognitive training is aimed to improve neuro-cognitive abilities such as memory, learning, attention and executive functioning. The conclusion of the article is that all interventions - non-computerized and computer-assisted, with and without strategy coaching and/or environmental adaptations - have effective components that can explain some positive results: an improved cognitive performance, lesser symptomatology and a better everyday functioning of participants. The authors, however, do not know whether these effects are sustainable over a longer period of time. They conclude that instead of trying to restore cognitive abilities per se, cognitive training should focus on the everyday functioning of the person through learning compensatory strategies or tasks combined with adaptations in the environment. Cognitive training might also be useful in combination with interventions like social skills training and vocational rehabilitation (Bell, et al., 2001).

This point is taken further by Bustillo et al. (2001) who reviewed research on the psychosocial treatment of patients with schizophrenia. They found that family therapy and assertive community treatment programs were very helpful in the prevention of psychotic relapses and re-hospitalization, but have much less effect on a patient's pervasive positive and negative symptoms, overall social functioning and his or her ability to find a regular job. Social skills training does indeed improve a patient's social skills - which may be translated into a more adaptive functioning in society - but has no clear effect on his or hers symptomatology, relapses or chances of getting a regular job; the latter is best achieved by using a “place-and-train” model with ongoing support to keep the job. Relatively simple, cheap, long-term psychoeducational approaches are very useful for treating persons with schizophrenia and related illnesses (Pekkala & Merinder, 2003).

For the large number of patients who continue to experience disabling psychotic symptoms, like delusions and hallucinations - despite an optimal pharmacological treatment - Bustillo et al. (2001) advise cognitive behavior therapy.

8.2 Teaching the curriculum “Later Life Planning for Adults with Mental Retardation” to older persons with chronic mental health problems

8.2.1 Introduction

Apart from the usual physical changes that can also be found in the general population - more problems in seeing and hearing, greater fatigue, lesser mobility and a proneness to all kind of illnesses (see Chapter II) - elderly persons with chronic mental health problems (CMHP) also have to deal with the consequences of changes in their environment, occupational activities, familiar living arrangements and losses of family members and friends. To prepare them for these changes the curriculum Later Life Planning for Adults with Mental Retardation could be helpful.

In order to find an answer to this supposition the following three questions were asked:

Would there be an increase in the knowledge of the participants after the training?

Would it be necessary to adapt the content of the original curriculum to this new group?

And would it be necessary to adapt the didactics of the original curriculum?

8.2.2 Methods and data collection

As in the care for persons with ID it has long been a tradition in the care for persons with CMHP to talk about them instead of talking to them. Doing so they are deprived of assuming an active role in planning their life and remaining involved in their social circle and society at large, two prerequisites for aging successfully (see Chapter II). Considering the positive effects the curriculum “Person-Centered Planning for Later Life” (Sutton et al., 1994) had for older persons with ID (see Chapters V and VI) it was hypothesized that the curriculum might also work for older persons with CMHP and therefore subsidy was sought to put these questions to the test.

The subsidy was granted and by the “Stichting Koningsheide”, a Dutch private foundation that aims to promote promising innovations in the field of mental health care, and by two organizations for supported living for persons with CMHP: the Regional Institution for Sheltered Living (RIBW) Heuvelland and Maasvallei in Maastricht and the RIBW Oostelijke Mijnstreek in Heerlen. The latter two organizations supply sheltered living arrangements for persons with CMHP, ranging from arrangements where people live in their own house with weekly visits by their

case manager, to houses where three or four persons live together who - on turn - do their own shopping and cooking, to group homes where twelve persons live and staff does the shopping and cooking.
As a first operational step, meetings were planned to inform case managers involved in the care for older persons with CMHP of the two organizations mentioned above about content and purpose of the curriculum Later Life Planning.
Like in the project for older persons with ID, participants in the curriculum had (preferably) to be over fifty years of age. As an extra requirement, persons in this new group also had to have lived at least five years out of the last ten years in either a psychiatric hospital, a socio-home of a psychiatric hospital or in a community based residence.
At the start of the project the case managers asked their clients if the idea of attending a course in which they could learn more about later-life planning appealed to them. Thirty-seven persons signed up to participate: 8 persons from the psychiatric hospital Vijverdal, 25 persons from RIBW Heuvelland en Maasvallei and 6 persons from RIBW Oostelijke Mijnstreek. Because it was meant as a program in adult education, and not as training or as therapy, persons were informed extensively about the curriculum and were individually asked if they would want to participate. Actually, all participants (or their legal representatives) had to sign an "Informed Consent Form" (see Appendix VII + VIII) in which they agreed to participate in the lessons and in the scientific evaluation carried out by Maastricht University. Persons who would want to stop during the training could do so without any consequences.

In a second meeting the case managers of the persons who agreed to participate were asked to be supportive to their clients, to help them with their home work and to give ample opportunities to practice the newly learned skills, especially in terms of choice-making.
Participants were divided over five groups, depending on the places where they lived and the home or hospital that was their main caregiver: three groups were in Maastricht, one in Sittard and one in Heerlen. Before starting the actual teaching a baseline evaluation (T1) was done with the "Later Life Planning Curriculum Pre-Test Post-Test for Older Persons with Mental Retardation/ Developmental Disabilities" (see Appendix II) and the "Later Life Planning Inventory for Older Persons with Mental Retardation/ Developmental Disabilities" (see Appendix I + II), developed by the Rehabilitation Research and Training Center on Aging with Mental Retardation, Institute on Disability and Human Development, the University of Illinois at Chicago and the Institute for Life-Span Development and Gerontology, the University of Akron. The case managers were given a demographic questionnaire (see Appendix III) to respond to.
Within three weeks after finishing the course a second evaluation (T2) was done, the period between T1 and T2 being less than five months.
The trainer (Maria van Laake) did the baseline (T1) interviews of all persons that showed an interest in attending the lessons in order to get to know her future students. The interviews lasted about an hour and were held in the places were people lived, sometimes in the living room, sometimes in participants' bedroom. Thirty-seven persons were asked the base-line interview questions. It was of course not adequate for the trainer and co-trainer to evaluate their own training, so co-trainers of other groups who did not know the students did the T2 interviews.

8.2.3 Characteristics of the program and the participants

All five courses were taught in places that were suited for the purpose; sometimes they were rented conference rooms, sometimes the teaching room was in a Day Activity Center. There were two trainers and five co-trainers. The second trainer started off as a co-trainer with the trainer (Maria van Laake) who developed her training skills in teaching the curriculum “Later Life planning for Adults with Mental Retardation”. All co-trainers were persons familiar with the students in their training group; sometimes they worked as activity coaches, sometimes they worked directly with the clients as case manager or mentor. In order to work smoothly as a team, trainer and co-trainer arranged for evaluation meetings before and after the lessons.

The Dutch version of the curriculum Later Life Planning has fifteen lessons, one individual concluding session and a graduation celebration (see Chapter VI). The idea was to start off with the same materials - Teachers Guidebook, Workbook and Posters - that were used in the Dutch research project of older persons with ID, and change or adapt the curriculum and material afterwards, if necessary. The only exception was the videotape: from a pre-view session with the manager of a group-home it became obvious that the tape could not be used without some serious re-editing: all persons with Down syndrome, persons that were clearly intellectually handicapped or persons walking around with dolls and bears had to be erased from the tape. Even after this close scrutiny, the tape was almost of no use in class. Any shot of a person with ID evoked pity from the students: poor people with whom they couldn’t identify themselves. The only part that “survived” was the part where the trainer explains the parts and functions of the human body.

During the teaching process from Lesson Two onward, however, it became ever more obvious that the wording used in the Teachers Guidebook needed adaptation, but the main concept - choice making - and the content of the six themes of the original curriculum remained unchanged. For most students two lessons on the same subject was one too many: it was quite apparent that although there were a number of students with mild ID, there was no need for repeated rehearsals: “You have told us that already last week. We are no ignorants.” Sometimes rephrasing was an option. One must always be careful, not to overestimate these students: they sometimes ward things off because they do not want to admit that in fact they do not know.

It proved to be very important to give participants many opportunities to hook in with stories from their own lives, stories from before and after they started their psychiatric career. Some have had normal working jobs or were married, some had children and some worried about their aging parents. Now they had the opportunity to tell their stories and everybody would listen with attention and respect. It helped to have coffee around and to allow a break to smoke cigarettes. One young female student offered to bake a cake - which she never actually did. But the idea was okay: coming together in a pleasant atmosphere to learn and listen to each other. As a rule, the trainer must be careful to keep the meetings relaxed and to keep tensions away, otherwise participants might not want to come back and drop out.

Sometimes a subject is too confrontational: when filling out the Circle of Relatives and Friends one elderly lady realized that she had lost all contact with three of her four children - not even her case manager did know that she had four kids, she knew only one son. Although not necessarily related to this fact, the woman almost became psychotic and attending the next lesson was impossible. Luckily she recovered rather quickly and at the end of the curriculum could celebrate a successful graduation with her co-students, case managers, family members, sponsors, trainers and other staff. Other participants were not so lucky: two elderly ladies from another group became depressed - not for the first time - and had to be hospitalized for several months. Their lives were sad stories of ever recurring depressive episodes, in fact all participants had a previous history of long and frequent hospital admissions.

Table 8.1 gives an oversight of participants’ characteristics at the start of the project in terms of gender, age, level of intellectual functioning, living situation, having structured day-activities outside the facility, social and leisure activities and impeding factors for participation in social activities.

Table 8.1 Characteristics of the participants (N=37) at baseline.

	absolute	%
Gender		
- male	11	29.7
- female	26	70.3
Age (mean age 56,0)		
- < 50	5	13.5
- 50 - 54	12	32.4
- 55 - 59	8	21.6
- 60 - 64	6	16.2
- > 65	6	16.2
Level of intellectual functioning		
- above average	2	5.4
- average	19	51.4
- mild ID	15	40.5
- unknown	1	2.7
Living situation		
- community residence	25	67.6
- independent living with case management	7	18.9
- apartment (with support)	5	13.5
Activities outside the facility/house		
- no	12	32.4
- yes	25	67.6
Social / Leisure activities		
- no	2	5.4
- yes	35	94.6
Impediments for participating in social activities		
- no	28	75.7
- yes	9	24.3

As can be seen five participants were younger than fifty years of age. Four were in their late forties and one, the young woman mentioned earlier, was thirty-one years. She was a patient for many years, witnessed a major fire in the institution in which one patient died, whereupon she set fire in her own room. She was seriously burned but recuperated. When in early 2001 her case manager heard about the course, he asked to invite her too because she was on the brink of going to live in an apartment of her own and in the lessons she could learn how to make friends and how to spend her leisure time. Apart from the repeated promise to bake a cake or bring homemade pancakes for all of us - which she planned to do in between her other household chores - she was studying for a high school degree. Not long after the graduation

ceremony in July 2001, it became clear that this was all too much for her: she relapsed and had to be re-hospitalized, not for the first time, and had to start all over again, also not for the first time.
Twenty-six of the participants were women; eleven were men. The youngest person was thirty-one, the young woman mentioned above, the oldest person was seventy-four years of age, the average age was fifty-six years. The majority of the participants (57%) had no intellectual disability, 40 % had mild intellectual disabilities.

Over two-thirds lived (67.6%) in community-based residences. In all facilities described below people have a room of their own with TV and radio sets where one can sit and sleep. The amount of support they get, especially in terms of cooking, cleaning and personal hygiene ranges from doing it all by yourself to full support. The closest to full support came the three students who lived in hospital settings: staff is present all day and dinner comes at noon from the hospital kitchen.
Three students in this “Vijverdal group” lived in a socio-home the hospital rents in the center of Maastricht. Here people live independently, with staff only popping in during daytime. A housekeeper - who also does the shopping with each person in turn - comes in in the evening to cook dinner that can be savored together in the big kitchen. One student lived in her own home and came to the hospital daily to take part in all sorts of day-activities.
Participants from one Maastricht RIBW group lived in group-homes situated in villages around Maastricht where six to twelve persons live together, staff being around all day. Staff and clients shop, cook and eat together; the evening meals are served at about six o’clock p.m.
Four students from another Maastricht RIBW group lived in a group-home with more supervision: the staff cooks meals, is present all day and everyone eats together at noon in the big living room. Two persons in this group lived independently with case management.
Participants of the Sittard RIBW group lived in three different places: in the city in two group-homes with eight and six persons respectively, and in a big farmhouse outside the city where twenty-four people live together in three groups of eight persons each. In all facilities staff is present during the day; in turn participants do the shopping for the meals, which are cooked together with a staff person in the evening. All groups have their own big living room where they can eat and sit together.
The Heerlen RIBW group lived together in an eight-person group-home. People take turns in shopping and cooking; meals are eaten together in the common sitting and dining room. Staff is present all day.
In all larger facilities outside the mental hospital staff leaves at ten p.m. After hours clients have a direct phone line with the staff person on duty if there might be trouble of any kind.

Almost all students participated in some kind of social or leisure activity. Some people still had their parents living in the neighborhood to visit, some met with family - mostly sisters - at a regular basis and some of the women visited their (married) children. Shopping for nice little things like earrings or bracelets and dining out with a friend were favorite pastimes for some of the elderly ladies, as was going to the market to buy oranges or apples. Men would go into town to have a glass of soda or a cup of coffee, mostly on their own, seldom together with others. Engaging in hobby’s - like some metal or wood working for men in local clubs - became ever more difficult because so many city councils stop subsidizing this kind of activities. Some participants complained of lack of money that prevented them for going into town more regularly to buy music tapes or see a movie. Sometimes they felt not well enough to go out or there was no staff present to accompany them into town. Sometimes people complained about transportation being too expensive or they just did not feel like leaving the house: for some sitting in their room, listening to music and smoking a cigarette was all they could manage for one day.

From the group of thirty-seven persons that did complete the baseline measures before starting the course (T1), only twenty-seven also completed the measurement of the follow up (T2). The main reason of the high number of dropouts can be found in the seriousness of participants’ psychiatric problems.
Reasons for dropping out were:

- one person did not want to start because he needed all his time to study the things his voices told him to;
- two persons stopped after the first lesson: before they had their mental breakdown they had good jobs in society and the content of the lesson did not appeal to them;
- one person became psychotic after lesson four;
- after lesson eight one Korsakov-patient stopped: her case manager said the inability to retain the material was too confrontational;
- one person had to stop because of a physical illness;
- one person was expelled because of unacceptable behavior - she farted, belched and finally fell asleep during lessons;
- two persons were hospitalized with a serious depression and could not participate in the final interview;
- one person did attend all lessons but refused a concluding interview.

This large number of dropouts marks a sharp difference with teaching the curriculum to the group of older adults with ID that was discussed in Chapter VI. Almost all students in those groups with five exceptions completed the course.
As can be deduced from the listed reasons of dropping out, persons with a dual diagnosis appear to live very much under the pressure of their mental health problems.

In Table 8.2 the ten dropouts are compared on some demographic characteristics with the twenty-seven persons that did finish the course.

Table 8.2 Differences between the response and non-response group on T1

	Response group (n=27)	Non-response group (n=10)
Gender		
- male	29%	30%
- female	71%	70%
Age		
- < 55	42%	50%
- 55 - 64	42%	30%
- > 65	16%	20%
Level of intellectual functioning		
- normal intelligence	63%	50%
- mild ID	33%	50%
- unknown	4%	-

One conclusion is that by losing about 25 % of the sample - which was already small - only a limited validity can be attributed to the generalization of the results for the population of persons with chronic mental health problems. Looking at the above demographic parameters, there is not much difference, however, between the response group and the non-response group. One should be aware though, that the picture could be much more complex when emotional or psychiatric disturbances - which were not measured - are compared between both groups.

8.3 Results

The question for the quantitative evaluation is: will there be a change in participants' knowledge after teaching the curriculum "Later Life Planning for older Adults with Mental Retardation" concerning the main six themes: Health and Well-Being, Leisure Time Activities, Work and Pension, Living Arrangements, Choice-making and Involvement in Personal Care Plans?
Based on the positive results mentioned earlier (see Chapter VI) the assumption was that persons with chronic mental health problems and persons with a dual diagnosis might benefit from the training, as many of them may not have had the opportunities to practice choice making and may learn (again) some abilities to make new friends and learn more about age appropriate leisure activities. In the following the results are presented.

8.3.1 Choice-making

Over the last years persons with CMHP too became more and more involved in choice making and the planning of their own lives. Their abilities in this field and their knowledge of their rights however may still be somewhat limited. In the chapters on Choice-Making their rights (and plights) are explained at great lengths: what does it mean for me personally when I choose to live in town, away from the psychiatric hospital with only my case manager visiting me once or twice a week? Choice making is practiced throughout the curriculum; it even starts at the very beginning when the person is asked does or doesn't he or she want to participate in the project?

Table 8.3 Choice Making Knowledge (score 0 - 8): change in knowledge (%) between T1 en T2.

	T1	T2	%
Total	3.44	4.96	+44.2*
Gender			
- male	4.22	4.67	+10.7*
- female	3.06	5.11	+67.0*
Level of ID			
- no ID	3.76	5.41	+43.9*
- mild ID	2.90	4.20	+44.8*

* matched t-test: p < .05

For all participants the total increase in knowledge concerning Choice-Making (Table 8.3) amounts to 44%, being a relevant and significant increase during the course's fifth months teaching period. The greatest increase can be found in female participants (67%). For all four subgroups - men and women persons with ID and persons with normal intelligence - the increase in knowledge concerning Choice Making is statistically significant.

8.3.2 Health and Well-Being

In the chapters of the curriculum dealing with Health and Well-Being participants learn about the physical changes that occur while aging and about making healthy choices: (preferably) doing daily physical exercises and eating healthy food - with none or only a little salt and sugar added to it and certainly with low fat - and at least two pieces of fruit each day. Making healthy choices keeps you healthy and fit.

Table 8.4 Health and Well-being (score 0 - 4): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	3.44	3.11	- 9.6
Gender			
- male	3.56	3.44	- 3.4
- female	3.39	2.94	-13.3
Level of ID			
- no ID	3.29	3.00	- 8.8
- mild ID	3.70	3.30	-10.8

* matched t-test: p < .05

Table 8.4 shows the differences before and after attending the course in the knowledge on healthy choice making of all participants, the changes in men and women and in persons with and without ID. All figures on all levels indicate a slight, but not significant decrease in participants’ knowledge instead of the expected increase. From the beginning most participants were well informed on the subject and did not learn anything new in the training. They could not stabilize their results at follow-up (ceiling effect).

8.3.3 Fitness

In the chapters on the need to exercise and make other healthy choices participants learn how important it is for aging persons to keep physically active and to be aware of eating healthy food. Part of the curriculum is small booklet with all kinds of simple exercises for older persons to do at home. Table 8.5 shows the results.

Table 8.5 Fitness (score 0 - 10): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	8.15	7.67	- 5.9
Gender			
- male	8.37	7.89	- 4.0
- female	8.11	7.56	- 6.8
Level of ID			
- no ID	8.53	7.24	-15.1*
- mild ID	7.50	8.40	+12.0

* matched t-test: p < .05

In total the group shows a lower average score on T2; this lower score can be found in every subgroup, but for the persons with mild ID. Persons without ID even have a statistically significant lower score on T2 than on T1.

8.3.4 Leisure Time Activities

Another important topic of the curriculum Later Life Planning is the lessons on Leisure Time Activities. Participants are told about the importance of participating in leisure-time activities and about active engagement versus inactivity. Several (local) opportunities are discussed like becoming a member of a folk-dance group or participating in social activities in the local senior center like playing billiards or cards.

Table 8.6 Leisure time activities (score 0 - 15): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	8.19	8.81	+ 7.6
Gender			
- male	8.00	10.44	+ 30.5
- female	8.28	8.00	- 3.4
Level of ID			
- no ID	9.24	8.00	- 13.4
- mild ID	6.40	10.20	+ 59.4*

* matched t-test: p < .05

Table 8.6 gives an overview of the knowledge of the participants before and after the intervention: the table shows a total increase of +7.6% on T2 over T1. The increase is high for men (+30.5%), while the women show a slight decrease. Noteworthy - and statistically significant - is the increase of T2 over T1 in the participants with mild ID: +59.4%. Before the course started they apparently had only scarce knowledge about things one can do in leisure time; the curriculum really did help them to find appropriate ways to spend their time off. Persons with normal intelligence had more knowledge at the start; they did not learn more during the course and showed a moderate decline in knowledge about leisure time activities at the follow-up measurement.

8.3.5 Work and Pension

The purpose of the lessons “Work and Pension” is to inform participants on the options of changing their work time from a full-time job to a part-time job and eventually retirement. Participants are told about the reasons why people might want to change their working rhythm or why some even want to stop working at all. Why - for instance - is it okay to work and why might it be good to change your work habits? The teacher gives information about (local) opportunities to change from full-time to part-time work or starting later in the morning and asks participants about their individual choices and wishes.

Table 8.7 Work en Pension (score 0 - 9): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	5.78	6.00	+ 3.8
Gender			
- male	6.22	6.44	+ 3.5
- female	5.56	5.78	+ 4.0
Level of ID			
- no ID	6.24	5.41	- 13.3
- mild ID	5.00	7.00	+ 40.0

* matched t-test: p < .05

In table 8.7 the results are shown on “Work and Pension”. After attending the curriculum both men and women did show a slight but statistically not significant increase in knowledge. A large increase (not statistically significant) in knowledge is - again - found in persons with mild ID (40%). Persons without ID showed a slight decrease in their knowledge (-13.3%).

8.3.6 Living Arrangements

In the lessons dealing with Living Arrangements participants learn about the (many) local possibilities and about the individual pros and cons of any arrangement. Often drastic changes are not possible - not old enough, too many (expected) relapses over time - and therefore a major part of the lessons is devoted to what things can be rearranged at present in one’s living situation and what things one can - eventually - do to improve the atmosphere in the house.

Table 8.8 Living Arrangements (score 0 - 4): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	3.30	3.33	+ 0.9
Gender			
- male	3.11	3.00	- 3.5
- female			+ 3.2
Level of ID			
- no ID	3.41	3.12	- 8.5
- mild ID	3.10	3.70	+ 19.4

* matched t-test: $p < .05$

Table 8.8 shows the results on “Living Arrangements”: as can be seen from the high scores on T1 and T2 almost all participants already knew a lot concerning possible Living Arrangements, although women (3.2%) and persons with mild ID (19.4%) gained extra knowledge. The results however, are statistically not significant.

8.3.7 Individual Care Plan

The last session of the training is an individual session in which the participant is encouraged to say what plans he or she has in the future concerning the six curriculum themes. If a person wants to join a folk dance group for instance, what needs to be done to get there, who can help obtaining this goal and what obstacles might one encounter in the endeavor. In the individual meeting all curriculum themes are shortly outlined again and sometimes - after thinking things over - participants present new ideas not mentioned earlier in the group sessions. In doing so his or her self-confidence is boosted and participants get trained for the “real thing”, his or her Individual Care Plan-meeting. Table 8.9. shows the results.

The whole group learned considerably about how Individual Care Plan-meetings (43.6%) work and how to speak out during the meeting. The increase in knowledge is statistically significant in all participants; the increase in knowledge between men and women is about the same, but persons with mild ID learned the most (62.5).

Table 8.9 Individual Care Plan-meeting (score 0 - 4): change in knowledge (%) between T1 and T2.

	T1	T2	%
Total	1.70	2.44	+43.6*
Gender			
- male	2.00	2.89	+44.5*
- female	1.56	2.22	+42.3*
Level of ID			
- no ID	1.76	2.35	+33.5*
- mild ID	1.60	2.60	+62.5*

* matched t-test: p < .05

8.4 Discussion

The training of the curriculum “Later Life Planning for Adults with Mental Retardation” was pursued to find an answer to the following three questions:

1. Can the curriculum Later Life Planning be used for persons with CMHP?
2. Within this group of patients is the curriculum more effective for persons with a dual diagnosis?
3. What changes in the curriculum are needed for use with persons with CMHP?

With regard to the first two questions there was a large difference in outcomes between persons with CMHP with and without intellectual disability. As can be seen from the tables presented in this chapter the course “Later Life Planning for Adults with Mental Retardation” certainly appeals more to persons with a dual diagnosis than to persons with “only” chronic mental health problems: persons with CMHP often performed at the same or even under their baseline measure. The reason for this finding might be that before becoming a person with CMHP, many of the men and women involved had a full life within society, were married with children and had regular jobs. Henceforth they were quite knowledgeable on a range of subjects taught in the curriculum like options for leisure time activities, work, pension and living arrangements. The course did tell them nothing new and some of them dropped out soon after the first lessons. All in all, ten out of the thirty-seven persons that took the baseline interview did not participate in the follow-up evaluation.

Of the remaining twenty-seven participants, 63% had a normal intelligence. The negative results on the follow-up measurement on several items for persons with a normal IQ indicates that they learned nothing new from the course that was originally developed for persons with ID. A decrease in knowledge at the follow-up measurement was found in Making Healthy Choices, Fitness, Leisure Time Activities, Work and Pension and Living Arrangements. The only two fields in which participants’ knowledge did increase statistically significant are in Choice Making and Individual Care Plan Meeting.

It is therefore clear that without adaptations in these five themes the course cannot is not very useful for persons with CMHP without ID. However for persons with CMHP and ID the outcomes of the course were very successful.

Table 8.10 Change in knowledge (%) for persons with CMHP and ID between T1 and T2.

	T1	T2	%
Choice making	2.90	4.20	+44.8*
Health and well-being	3.70	3.30	- 10.8
Fitness	7.50	8.40	+12.0
Leisure time activities	6.40	10.20	+59.4*
Work and Pension	5.00	7.00	+40.0
Living arrangements	3.10	3.70	+19.4
Individual Care Plan Meeting	1.60	2.60	+62.5*

* matched t-test: $p < .05$

Indeed, in some fields a clear increase is found in the knowledge of persons with a dual diagnosis: notably in the fields of “Choice-Making” - the leading theme of the curriculum - “Individual Care-plan-making”, and to some extent “Leisure Time”. Remarkable, but on second thoughts explainable, is that persons with ID showed the greater increase in knowledge on T2. They started off at a lower level of knowledge than their colleagues without ID, gained more knowledge in the course and therefore ended higher at the end. The course was originally designed for persons with ID and therefore the materials are more geared to the participants with ID than to the non-ID persons, who as said, were already knowledgeable at most topics.

The dropout rates during the course were not higher for persons without ID as could be expected. However, the results could be influenced by the lack of support and the heterogeneousness of the groups. As already mentioned in Chapter III the support of the individual care persons are essential for successful participation in the course. Care persons should be there to help the student plan his or her homework within a realistic planning of the week’s other activities. The care persons should also plan enough time in their work schedule to be able to talk things over and so discuss the choices made. In this way they can help the person to keep his promises: to eat more healthy food and go for a walk more often.
Family members can also be instrumental in helping the student to abide by his (healthy) choices. It is therefore important to inform family members and friends about the aims of the training and to tell them how they can help. It should be clear from the beginning that the training is not meant to be a cozy coffee hour for the participants. Case managers, individual care persons, family and friends should be aware of the fact that students need support, not only during the training period, but also afterwards when the newly learned faculties - choice-making for instance - should be integrated in their daily lives.

Persons who see their case manager only once or twice a week do not easily mix with persons who live in residential facilities where staff is present all day long, nor do they learn from each other for that matter. Another important reason may have been the level of psychopathology within the group: too much disruptive behavior can make the training sessions very unpleasant to attend to. Some persons never even started the training because the idea of having to attend regular meetings impeded too much upon their yearlong established daily routines. A last reason for quitting the course was the rapidly deteriorating mental health condition of some participants during the training.

Because of the small number of the persons involved, the generalization of the results of this project to the greater group of persons with CMHP does not go unhampered. Although there appears to be almost no difference in the distinctions between persons that stayed in the project and the drop-outs on the three investigated dimensions of gender, age and level of ID (see Table 8.2), there may be other characteristics like mental health status or duration of stay - and hence hospitalization effects - that could be major determinants for dropping out.

The aim of the statistical analyses performed was to evaluate if the reported changes in participants' knowledge over time are larger than can be expected by mere chance. The analysis involves changes in knowledge on the main six themes of the curriculum Later Life Planning: Choice-making, Exercise, Leisure-time activities, Work and Pension, and Living Arrangements, resulting in participants' greater involvement in their Individual Care Plan Meetings.

In this study the same test instruments were used as for persons with ID (Chapter VI) and the interviews were also done in the same way. Participants were asked by interviewers to give answers to long lists with rather simple questions, because persons with ID often are not able to read and write (Derks et al., 1994). Persons with CMHP, however, are most of the times quite able to read and write and might even resent verbal interviews. It might have been wiser to give participants in these project questionnaires they themselves had to fill in.
With regard to the level of knowledge persons with CMHP scored at the max of the asked level of knowledge before the start of the project: for them there were hardly any new things to learn. When this curriculum is again taught to this target group one has to dive deeper into the subjects - especially the lessons on patients' rights and (leisure time) activities - and an eventual evaluation of their knowledge should be more differentiated.

The lessons on the consequences of aging and why it is important to eat healthy food were more or less lost on the participants. It is a little puzzling that some gave less correct answers at the end of the project than they did at the beginning. It may be because these issues were discussed in the beginning of the curriculum and participants had to get used to the idea of being a student again. It may also be that learning about the advantages of eating healthy food, and the deteriorating health effects of smoking lots of cigarettes and drinking many mugs of coffee came too close to what they actually do during the day. They simply resisted the information, plugged their ears and learned nothing new.

It is a well-known fact in the care for persons with CMHP that many are prone to promising the world and forgetting it the next day. A notorious example in this curriculum is the request - and the following promise - to exercise daily. Participants know it is good for the body, it keeps you fit, and eventually you will live longer. Unfortunately they stop fairly quickly, and although they promise to start again, they hardly ever do. The heads of many participants are just too full with all kinds of things - and if and when not stimulated enough - they fall back into their old habits of smoking and sitting inside the house for the most of the day all too soon. At a visit of the trainer to the group home a few months after the course stopped, it was all too obvious. People said they enjoyed the lessons greatly, they learned a lot, the graduation ceremony was super, but the picture becomes ever clearer. Many approaches have been tried with this chronic group, they have lived in a number of places, inside the hospital and outside, and now they are fifty years or over and the place they live in is the best they will be able to get. Some care persons even fear a backlash for their clients when they age and some may have to go back to the psychiatric hospital because their behavior is too disruptive for the place they live in at present.

Literature shows (Dosen, 1995; Petry, 1995) that persons with a dual diagnosis are especially vulnerable to the strains society puts on them. Not only do they often suffer from (chronic) depression and anxiety disorders (Stravakaki, 1999), because of their limited cognitive abilities they are also at a disadvantage to plan and oversee the future and the steps that are needed to accomplish certain goals (Petry, 1995). Disappointed by life they often fall into a downwards spiral of self hate which may lead them to physically hurt themselves, e.g., by cutting their arms or by jumping off bridges into the river. (Derks & Barnard, 1995).

The greatest difference between persons with ID and persons with a dual diagnosis is that most persons with CMHP have led quite normal lives before they were hospitalized, whereas almost all persons with ID were diagnosed as such from an early age on. The first group went to a normal school, graduated, had jobs and friends, some got married and had children: they were full members of society. Their “social” handicap is the result of their mental health problem, which occurred to them when they were grown-ups.
The original focus of the curriculum “Later Life Planning” were older persons with an intellectual disability who, when they were young, did not have the chance to take an active role in society and were shunned from normal societal interactions and henceforth the chance to learn about the real world. This knick in their lives is the most striking difference between persons with chronic mental health problems and persons with ID.

One of the greatest pitfalls in teaching a group of persons with CMHP is that they often act as if they are omniscient and are fully integrated in society. Indeed they go into town and have a cup of coffee, but they talk to no one and always go to the same pub where the bar owner accepts there silence and queer behavior. Some say the lessons are boring and they hear nothing new to hide the fact that next time they haven’t a clue about the things told in the previous lesson. People may not want to place their system of defenses in jeopardy - to which they are fully entitled - and quit. The best chances to keep persons involved in the training is to elaborate on the content of the lessons, a major difference with teaching to persons with ID, where the trainer has to repeat new things as often as possible. Here they often say, “You told that already; we are no simpletons.”
In both groups the trainer has to show respect for the way people are and ask if they want to elaborate on things or tell their own experiences. If sometimes an odd remark pops up from a student that is known with psychotic episodes, it is better to pay short attention to what he or she is saying, because if one doesn’t, the “queer” thoughts keep on disturbing his or her thoughts and come back more intense than before on a moment one is absolutely not prepared. In doing so “the steam gets out of the kettle” and the student can be brought back to the here and now reality of the training.

Persons with a bi-polar depression often are - not surprisingly - extremely enthusiastic students in their “up period”, but a commitment of four months to follow the lessons is often too long for them; some are already in their “down period” before “graduation”. How contradictory it may sound from persons with CMHP, whose lives for years and years look the same to us, many are just not prepared to commit themselves for such a long period. This and the fact that in the original training things are so often repeated, a number of changes are proposed.

8.5 Proposed adaptations to the curriculum “Later Life Planning for Persons with Chronic Mental Health Problems”

The different outcomes for persons with and without ID urge for adaptations of the curriculum (Question III) In order to keep a group of persons with CMHP interested it is important to make the lessons as informative as possible. Telling the same thing twice in the same words evokes protest, but rephrasing and restating does not. Participants are often glad to share their own experiences and elaborate on them. Many never had the chance to tell or nobody paid any attention when they did: they were patients and that was it. In the curriculum, participants are valued and everybody is interested in their stories - provided they are not too much out of touch with reality. Another important thing is to ask experts on care or patient’s rights for instance, to come to a lesson to answer their questions.

8.5.1 Lesson One

In Lesson One - introducing the curriculum - the trainer can ask if participants would like to invite somebody knowledgeable to answer questions they might have in relation to for instance, Rights, Health or Living Arrangements. It is wise to ask right at the beginning because doctors, physiotherapists or whoever might have a busy agenda and have to plan well in advance. If a doctor is willing to come it is wise to plan extra time: very often participants have so many questions that there is not enough time for the normal routine of checking homework, recapping the previous lesson and introducing and explaining the next subject. It is important however to make this connection to the “outside” world, not only to increase participants’ knowledge but also to give them the opportunity to relate to the “normal” world in a non-patient way.

8.5.2 Lesson Two

The main subject of Lesson Two is Choice-Making. To make things more tangible the trainer can ask participants to cut pictures or photographs out of old magazines or papers connected to a specific theme like “Celebrate your Life” or “My Favorite Hero’s”. Some protest because they think it is way too childish, but most of the times, at the end of the day, everybody enthusiastically engages in pasting the cuts together into a beautiful poster.

8.5.3 Lesson Three

In Lesson Three the Choice-Making Chart is introduced. In both groups - in persons with ID and in persons with CMHP - choice-making starts with simple things and eventually becomes more complex: after years of living in mental hospitals one participant choose to live in a home for physically handicapped persons; others wanted to have more contact with their relatives.

Another important subject in this lesson is “Rights and Plights”. Things can be made explicit by writing on a sheet a person’s right first - I can go out to the movies at night - followed by one’s plight - I have to tell my housemate when I will be back. It appeared that one of the most important rights was “to sit on the couch”, but only after one’s house chores were done: clearing the table or doing the dishes. This group of people is fast in getting the clue of this lesson which leaves enough time after the smoke and coffee break to invite the extern expert of choice.

8.5.4 Lesson Four

In this lesson the process and consequences of aging are explained. For many people the video-clip “This is your body” is an eye-opener; only a few are familiar with the anatomic doll we all know from our high school years. Most participants know the consequences of aging, but the importance of doing - and keep doing - physical exercises remains difficult to internalize: some will just never do it - no matter what they promise - others overdo and complain next time of all kinds of aches and pains. At the end of the curriculum only one or two persons were still engaged, the others stopped long time ago never mind claiming the opposite.

The greatest adaptations are proposed in connection with the original Lessons Five and Six. Aging and its bodily consequences are hard stuff to grasp for older adults with ID; it takes a lot of explaining before they understand how to do physical exercises - almost every exercise has to be shown - and the importance of making healthy choices. In the original curriculum three lessons are devoted to these subjects, but residential psychiatric patients are quicker and get easily bored with the many recaps in the original text. This is the main reason why the three “old” lessons were mopped up in one new lesson Four “Health”. The homework is also newly designed: making a physical exercise scheme no longer is the most important thing. Attention is shifted to the (new) content of Lesson Four: what are the consequences of aging, why is it important to buy and eat healthy food and what are your impediments for doing exercises. Several participants were quite unfit and had all kinds of physical troubles that hindered them in doing exercises or their physician explicitly forbid them to exercise because of possible heart failure or shortness of breath.

8.5.5 Lesson Five

The subject of the new Lesson Five is Leisure Time Activities, a subject on which both groups differ greatly: hardly any collection of stamps survived the move into the psychiatric hospital, as the many porcelain figures did not survive the moves from one house in the community to the next. But there is another more striking difference between the two groups: older persons with ID - at least in the Netherlands - have a busy life. When they do not work, they go to day-activity centers, there are all sorts of clubs and activities to attend, their days are very full and more often than not it is plain difficult to even try to organize a Later Life Planning Curriculum for them.
The world of persons with CMHP however is a completely different one: apart from some obligatory day activities, their leisure time looks very bleak. Because of financial cuts community centers had to close down activities, like walk-in coffee mornings, and card or knitting clubs. Many persons living in their own house or in community-based facilities are thus obliged to stay indoors and watch TV, drink coffee or smoke cigarettes. Most of the time they have only little money to spend and

- when the cigarettes are bought - hardly any money is left to go into town to see a movie or drink a glass of beer.
They also miss the curiosity that helps persons with ID to go into the outside world and start something new. Many persons with CMHP have been there and done that, with little or no success. Some are in a down period for many months and some others just don't have the energy to start something "nice". Participants in all groups though were very enthusiastic about the field trip that is part of this chapter and discussed at great length the many trip options that they found in leaflets from the local tourist office.

8.5.6 Lesson Six

In discussing Lesson Six - Work and Retirement - the same kind of problems that were discussed in connection with Lesson Five popped up: hardly any person with CMHP has a regular job. Some have some structured day activities, but as most of them have worked before they fell ill, they know all too well that this is not work at all. Discussions on early retirement or working part-time are therefore pointless: day activities are a scarce commodity and stopping is no option, the consequence being staying at home and doing household chores. People get under stimulated and have too much idle time. Most participants liked to talk about the jobs they had done. This might be a good time to invite somebody who knows about pensions or (financial) rules and regulations one faces when one is a dependent upon a service provider for long term mental health care.

8.5.7 Lessons Seven and Eight

Lessons Eleven and Twelve from the ID training didn't need to be changed and are Lessons Seven and Eight in this curriculum. Having a social network may be problematic both in older adults with ID and in older psychiatric patients, but experience in this project shows a dramatic lack of close relations in the latter group. After a short introduction - how to make and keep friends - the trainer introduces the "Circle of Friends". The nucleus of the first circle is the participant and around him or her are the various other circles: in the first circle one writes the names of relatives and closest friends, in the second one good friends and in the third and last the names of people one knows, but are not friends.
In the many sessions with older persons with ID all circles almost always contained many names: names of roommates in the first circle, staff and other personnel in the second and the bus drivers name in the third.

In this group the picture is quite different: with the female participants the first circle often has the names of children and grandchildren, the men often mention their parents - when and if alive - their girl-friend or a friend they still see. In the second circle there are one or two names; from a friend they sometimes see in town or from a former neighbor, no names of staff or other professionals. The third circle is often empty: they talk to no one when riding on the bus or doing errands.

The fact that so many older persons with ID call staff their friends and persons with CMHP are not inclined to do so is not easily explained. It may be because of a greater turnover of staff in mental health facilities and persons with CMHP do not look at staff as their confidents, whereas in the care for persons with ID staff often is looked upon as the source of help and comfort.

The reason why there are two lessons planned on this subject has the following reasons:

1. it is quite boring to write down names of family members and friends of six to eight persons in one lesson;
2. some people are not quite sure if a person is a close friend or an acquaintance: discussing the options is time consuming;
3. some participants are very reluctant in discussing this subject: giving the person time to think things over helps. And even then.... one participant was so upset when she realized that she was almost all alone that her case manager had to be very persuasive in order to get her to the last lesson.

8.5.8 Lesson Nine

In the last lesson on “Living Arrangements” participants discuss how they can make their home or facility more comfortable to live in. One can talk about what to do to create a nice atmosphere in the house or - more practical - how to make something nice to decorate the house.

Some participants have seen it all: they started their career in the mental health circuit in the big old institutions with big wards and no privacy. Some others had only a short psychotic episode and live in their own house with the support of a case manager. But for almost all one can safely say that their present living arrangement is the best they can cope with. Unlike older adults with ID - because of their psychiatric illness and/or behavioral problems - they often will not be able to share an apartment with a friend.

This lesson can be used to discuss future living arrangements with a manager of a community based facility, what are the options and how much extra support can be given when a person wants to stay in his or her house.

8.5.9 Lesson Ten

Already in the Dutch version of the Later Life Curriculum for Older Adults with ID the last lesson was changed from a lesson with the group to a final individual interview. In an individual interview trainer and co-trainer can focus their attention to one person with his or her individual possibilities and wishes and one can invite the person’s family or case manager to ensure the transfer from the learning situation to real life. Many persons with ID wanted to make all kinds of changes: join a dance club and stop to work. But these participants were less eager: their life was fine, living arrangements were okay, they wished for nothing. They had enjoyed the curriculum sessions though: they had learned a lot - especially in terms of what they were still able to do - and they had discussed things with normal people from a normal perspective: as normal persons not as patients.

Case managers reported that their clients went into town more often, even together with a housemate, and had more self esteem, the course’s certificate being the tangible proof of their improvement.

8.5.10 Closing celebration

The graduation of the participants of the curriculum took place in a very nice hotel in town. It was very touching to see that some ladies in the groups - when the announcement of the graduation in the hotel was made - started to discuss the best clothes to wear to the occasion: what if it rained, what if it was hot weather and who would all come to the celebration?

All worries disappeared when coffee, tea and cake was served: some saw old acquaintances, some saw staff they hadn't seen in years because they had switched jobs. Participants could bring their family and friends to the celebration and several managers had also taken the opportunity to join.
The highlight of the event however was the actual graduation ceremony: every participant stepped forward and got his or her certificate from a real professor - professor Haveman, the supervisor of the project.

8.5.11 Videotape and photographs

As was mentioned earlier the videotape that was used in the training for persons with ID was of little use in this course. What had proven to be stimulating for students with ID, proved to be utterly insulting to these participants even though all images of grown-ups with dolls or persons with Down syndrome were removed from the video tape. Only the part of the video that explains the functions of the human body was valued. One should also make sparse use of the pictures of the Life Line and the Posters: these students get easily bored - and upset - when they feel treated like ignorants.

8.6 Recommendations

It is important that before the curriculum starts, the individual care persons or case managers are informed on what the aims of the course are and what their role will be in the process. It is essential that they plan for adequate time to assist the student with his or her homework and offer opportunities to practice what was learned in the lessons, with a special focus on choice-making.

The role of the individual care person is a very important one. He or she has to facilitate participant's learning process in order to obtain a maximum effect. Therefore

1. every participant has to have one;
2. every care person has to be aware of the aims of the curriculum and the items that will be discussed;
3. he or she has to know what his or her role is during the curriculum;
4. he care person has to help the student with the homework and has to help realize his or her choices;
5. if the care person is on leave he or she has to find a colleague to help out;
6. the individual care person has to be the spider in the web if more caretakers are involved in the student's life.

The curriculum items do appeal to participants, but in the original form they are too often repeated and too often rehearsed for this specific group of people. Therefore the curriculum is rewritten into a shorter version with only nine lessons and a closing individual interview (van Laake, Haveman, Reijnders, 2002). This means that there are now two (Dutch) versions of the original curriculum "Person Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation (Sutton et al, 1994) namely: "Cursus ouderdomsplanning voor mensen met een verstandelijke handicap" and "Making up Your Own Mind (van Laake et al., 2002).

The persons participating in the curriculum felt very serious about it: it was they who were participating and not staff members, they have to do homework and they got a lot of individual attention during the lessons.

The last individual session is a very important one. The student and his or her care person - sometimes family members or friends are invited too - come together with the trainer and co-trainer to evaluate the curriculum and to make concrete plans for the future. It is essential that these plans be integrated in the student’s Individual Care Plan so that they will be taken seriously and will be pursuit by the responsible service agency.

For many students joining the curriculum is an important step in their rehabilitation process: they are fully involved, their opinion is valued and their self-confidence is boosted, at the end of the course they are better capable of making up their own mind.

Chapter IX

Conclusions and recommendations

For long, traditional images of aging painted a rather dismal picture of elderly people. They were seen as prone to disease and senility, there surely was a loss of faculties, they were sexless and unproductive, inflexible and unable to learn, powerless and dependent, and they were inclined to withdraw from society. This picture of decline and loss, dependence and being in need of care is to a great extent untrue and unfair for present day elderly persons in the general population, but - when subscribed to - creates a double jeopardy for aging people with ID, who are confronted with discrimination on the basis of both age and disability.

A much more positive paradigm is found in the concept of successful aging, which was presented in the first chapter. The prerequisites for successful aging or aging well are: avoiding disease and disability, the maintenance of a sufficient level of cognitive functioning, and a continuing engagement with life (Rowe and Kahn, 1997, 1998). The overall goal of aging well should be “adding life to years and not just years to life” (Minkler & Fadem, 2002). Although aging well is not always within the reach of the individual and depends very much upon the individual’s starting point and future perspective, active involvement in leisure and social activities is essential, together with good health and financial security (Schaie, 1983).
An important aspect in this process is choice making. Exercising choices helps a person to create a successful and productive life (Krain, 1995). All these positive research findings imply that there are choices to be made: many of the age-associated problems are not the inevitable outcome of normal aging, but are due to lifestyle decisions. Decline and loss can be avoided through individual change strategies.
This perspective on aging bears in it the risk of overemphasizing personal responsibility and could lead to blaming individuals for unsuccessful aging. It ignores earlier parts of the life course and broader factors on aging like social inequalities and unequal life chances connected to disability, gender, class and ethnicity. It may even further stigmatize and marginalize persons aging with ID.

In promoting the concept of successful aging for aging persons with ID, it is therefore important to address these earlier life disadvantages that are not due to individual life choices. This may be achieved through a collective commitment to support a full citizenship for persons with ID, with respect for the diversity within this group. A full citizenship includes: equal rights, inclusion into society, and choice and self-determination. This may not be easily done because of lack of resources and a poor translation of this policy into practice, and of quality and nature of support.

In general one can say that the needs of aging persons with ID do not differ much from their needs during other parts of the life course:

- A sense of security: attention to physical and psychological needs, to feel safe from pain or discomfort and receive competent, sensitive care.
- A sense of continuity: recognition of the individual’s biography and connection with his or her past.

- A sense of belonging: meaningful relationships with family and friends and being part of a chosen community or group.
- A sense of purpose: engagement in purposeful activity, ability to identify and pursue goals and exercise choice.
- A sense of achievement: opportunities to meet meaningful goals and make a recognized and valued contribution.
- A sense of significance: feeling recognized and valued as a person of worth, that one matters as a person (Bigby, 2004).

Back in 1968 Nirje formulated his then groundbreaking ideas about normalization, which formed the basis of his “Theory of Senses”. In his view, persons with a disability are entitled to:

- a normal rhythm of the day - sleeping, getting up, having breakfast, work, leisure time, and so on;
- a normal rhythm of the week - work during the week, enjoy weekend and holidays;
- a normal rhythm of the year - Holiday Season, common holidays;
- a normal life - school, choosing a profession, leaving the parental home, working life, pension;
- normal recognition as a fellow citizen - rights and duties, choice and decision making;
- normal sexual relationships - within the societal context;
- normal economic position - for instance through work;
- normal living situation - private room, small living arrangements, choose own decorations, have a say in whom to live with, and so on.

The aim of normalization as Nirje saw it was not a mere physical, social or functional integration into general organizations for work, recreation or housing, but the mutually beneficial osmosis of handicapped and non-handicapped citizens living together - the aim not being to “normalize” handicapped people but to offer them a “normal” working, recreational, and living environment.

There are, however, a few premises that have to be fulfilled in order to realize the principles of normalization:

- persons in the general society have to be prepared and capable of accepting and welcoming persons with a disability in their midst as fellow citizens, whatever the seriousness or kind of the disability;
- persons with a disability are capable of fulfilling the “normal” social roles and responsibilities;
- governments, service providers, and insurance companies agree on these principles and are willing to realize them.

Over the last years, the Dutch government - and in its footsteps Dutch service providers - has made the pursuit of normalization the centerpiece of its policies (Nota “Onder Anderen”, 1993). Care for persons with a disability had to be taken away from the traditional institutions and given to ambulatory services that were embedded in society and had an easier access to clubs and organizations that could provide leisure time activities in community homes or (general) senior centers. Persons with a disability should apply for an apartment with (general) housing companies and they should see a general practitioner instead of the hospital doctor.

If the ideas are so good and are so broadly supported by both the Dutch Government and service providers, why do we - in the Netherlands - still have institutions, and why is it so difficult to integrate persons with ID or chronic mental health problems into society?

Looking at the first premise, from messages delivered by various news media it is clear that the stance “Not in my backyard” is more often heard than a welcoming song in a neighborhood where a socio-home for handicapped persons is planned. Apparently, people in the general society agree with the government’s ideas as long as they are not bothered themselves.

It is also very difficult to fulfill the second premise: research (Overkamp, 2000) shows that when persons with ID leave the institution the number of their social contacts does not increase, thereby hampering their social integration and the fulfillment of their social roles. Instead, this lack of informal social contacts often leads to feelings of insecurity and anxiety.

Although over the last years many persons with a disability have left the institution, institutions still exist. The Netherlands is - together with Poland - in the top three of European countries with the highest portion of its population living in an institution - these include mental hospitals, nursing homes and institutions for persons with ID (Haveman, 2004).

The following factors may have contributed to the slowing down of the de-institutionalization process in the Netherlands:

- although service providers were encouraged to draw up alternative care plans for their clients, the government failed to provide a legal back-up through obligatory national laws;
- because the money to fund service providers is distributed by health insurance companies and not by the government, no financial pressure could be applied by the government to promote the desired change;
- to ensure greater local involvement in the planning for new and alternative services, the parliament took the planning away from the national government and gave it to the provinces. Provincial governments, however, lacked the national policy perspective and were not inclined to take decisive action, precisely because of their greater local involvement;
- there was some strong resistance against the national government’s plans to de-institutionalize from organizations of parents, who felt that their children would be less safe in the society at large; parents feared that their children might be called names or even be mistreated;
- because of this fierce opposition provincial and national administrations gave in - the last thing they wanted was disturbing their good relationships with the well-organized and very influential parent and client organizations;
- another reason may be found in the fact that in the Netherlands, in the sixties and seventies of the last century, much money was spend on the renovation, rebuilding or modernization of old buildings, in this way realizing part of the very goals of normalization: de-concentration, functional differentiation, and small-scale living arrangements. That is why the quality of the buildings, their location, and quality of staff were more favorable than in the countries that took a lead in the normalization process;

- which leads to the view held by governors that to engage fully in a de-institutionalization process would lead to a destruction of capital and - possibly - to a decrease in quality of care;
- the last reason is also a financial one: the discrepancy between the interests of the individual client and the interests of the larger institution. To ensure quality of care, a certain amount of money is needed, and this money is largely “earned” through the constant supply of money for clients with serious intellectual disabilities or chronic mental health problems.

It may be that now, at the beginning of a new century, there are new opportunities to renew efforts to realize the ideals of normalization and de-institutionalization. The once modern buildings of the seventies are looked upon today as being old-fashioned and out of touch with modern standards of care, and - most important for financial managers - the then invested money is largely depreciated by now.

So it is time for a new start

The conclusions presented in this thesis on the importance of choice and decision making in the process of aging well - for persons with and without ID - underscore the importance of the ideals of normalization. Persons with disabilities living a ”normal” life can make choices to arrange their lives the way they want them. Choice making, however, does not come naturally and oftentimes has to be learned. Persons with ID often have not had the chance or opportunities to learn how to make choices. The course “Later Life Planning for Adults with Mental Retardation” and its spin off, the “Curriculum on Loss, Death and Dying”, teach individuals with ID how to make choices and, considering the results of the many courses given to date, appear to have done so successfully, irrespective of the subject. More importantly, acquired knowledge about choice making was maintained over time.

Because of the positive results of the projects described in this dissertation, courses on choice making and later life planning should become a part of the adult education programs of service providers. The question is whether courses should be offered by centers for adult education - as might be proposed because of normalization principles - or by service providers for persons with ID.
Centers for adult education are independent, students subscribe on a voluntary basis, there is less social control, and a student with ID feels very empowered in being a citizen who has enrolled in a course.
But, it may be difficult to get to an adult education center: it is too far away, the bus is too expensive, or a student may be physically handicapped or cannot travel alone. The course may be too expensive, or the content may not be in line with a person’s experiences and expectations.
Another drawback - also observed in teaching the curriculum in the Netherlands - was that, when the teacher and the assistant both met the students only in day activity centers and the home environment of the student was not directly involved, transfer of knowledge and skills to daily living situations was very hard to achieve. Although everything was done to ensure this transfer, experience has shown that when the staff is not constantly involved in a student’s learning process, the student learns and evolves, but the staff does not evolve at the same speed or in the same direction.

Also, a client's newly acquired choice making abilities are better integrated in the Individual Care Plan if the course "Later Life Planning" is organized within or with strong involvement of his or her main service provider. If not, a great deal of communication between teacher and service provider is needed.

In the Netherlands, a major step forward in the realization of the ideals of normalization has been set by the introduction of a "Persoonsgebonden Budget" (Individual Budget) for persons with ID and CMHP. This program encompasses the option for each such person - to be named "client" by the health insurance provider - to receive a certain amount of money with which he or she can buy care - any care, ranging from day activities, to a cleaning lady, to a specialized nurse. This program offers more choices for the individual client: together with his or her care person a choice can be made within the limits of the given Individual Budget. This means that before an actual choice can be made, the person with ID or CMHP should be aware of the many choices that are available. And that is where the course "Later Life Planning" comes in. When adapted to the demands of the various participants, the adult education courses "Later Life Planning for Adults with ID" and "Later Life Planning for Adults with CMHP" can teach each individual what he or she can realize within his or her own possibilities. At the end of the course, participants' wishes have to be written down and are eventually transferred to the client's Individual Care Plan. The empowerment, which - as was explained in Chapter IV - is also an aim of the course, enables the client to have a meaningful exchange of ideas and wishes with his or her care person.

When the government and its agents, the public, clients, and care persons alike develop a realistic perspective on the ideals of normalization - persons with a disability living a normal life according to their disabilities - a new dawn may arrive. There are, however, new impediments looming: a greater insecurity in the society at large and diminishing funding for care programs now that large numbers of "baby boomers" are aging.
It is immanent that future government plans have to find an answer to these new challenges of the twenty-first century.

Recommendations for further research

1. Although the Dutch research design included a semi long-term evaluation three months after the course ended, it would be very interesting to see what the results concerning knowledge of the various curriculum aspects and satisfaction would be over a longer period of time, for example one year later. Would, for instance, the effect of the curriculum on knowledge of choice making opportunities increase further, or would it stabilize over time?

2. A systematic evaluation of the Individual Care Plans still needs to be performed, in terms of what (financial) means were necessary to realize the set goals, who did what, and who was responsible for the realization of these goals.

3. Another question for future research is whether the increase in knowledge of choice-making opportunities leads to an increase in participants' abilities and to a greater assertiveness.

4. An outcome not pursued systematically in the research presented in this thesis is the generalization of the learning effects of the curriculum to participants' everyday life. How, for instance, did the course affect the client/care person interaction? Now there is only scarce evidence from phone calls to the trainer, in which a care person complained that her client would ask for the reason why whenever she told him to perform a certain house chore. Another care person told, with a certain pride, that his client had insisted on being present at his ICP meeting because that was a right he had learned about in the course! Are these just incidents, or did participants indeed transfer things they learned in the lessons to everyday life?

5. To attain maximum transfer to everyday situations, it would be recommendable to teach curriculum students only the basics - like choice-making. After they have learned the basics, students could come together on a weekly basis and discuss the various aspects of aging, guided by their own choices as written down on the Choice Chart.

6. Another perspective that was not followed up systematically is how participants actually experienced the curriculum. Here again, only some incidental comments were recorded, like “We would love to join another course again”.

7. The curriculum is tailored mainly to persons with mild and moderate ID; learning about choice-making opportunities should also be available to persons with severe ID. In that case, the curriculum should be transformed so that care persons can teach their individual clients with severe ID to recognize choice-making opportunities, like deciding what to eat, what to wear, and what to do in leisure time.

8. The curriculum should be extended with lessons on financial matters.

9. Another item that is not included in the curriculum is sexuality. Present day adults with ID often wrestle with questions like “How do I find a partner?” or when they have found one, “Can we have a baby?” It is recommendable to have appropriate course material to discuss these matters in a systematic way in a group of like-minded persons with ID who have asked themselves these questions.

10. The positive results of teaching the curriculum in Germany (Haveman et al., 1999, 2000) and the enthusiasm with which the train-the-trainer courses have been met in Switzerland and Austria lead to the conclusion that the curriculum should be translated into other (European) languages, e.g. French, Spanish, and Italian.

11. Aging with ID is not yet a common theme in Middle European countries. Some of these countries have only just started to bring their services for persons with ID up to Western European standards. Much advocacy needs to be done in this respect, and with the help of European funds much needed translation, adaptation and research should start.

12. The curriculum is a major overhaul exercise for the current? Contemporary? cohort of older persons with ID. Perhaps in a few years time, adults with ID may

have learned how to make choices or how to make (and maintain) friends in school. The course in its present format will be redundant by then. So the question is: Is it necessary to learn about new things by attending a course, or can care persons raise certain questions whenever it seems appropriate - for example a discussion about life, death, and dying when a cat is found dead on the street?

13. In Germany, persons with a moderate ID learned more than persons with a mild ID; in order to achieve the same increase in knowledge in persons with a mild ID, the course material should be enriched with more examples and perhaps speeded up and intensified.

14. One explanation for the lack of increased knowledge after the course in persons with mild ID may be that the assessment scale that was used was not adequate for persons with a mild ID. The scale underestimated the knowledge in persons with mild ID before the course started. In the future, new and more items should be included in the course material.

Abstract

Over the last years the world has seen a growing number of persons who live far into their seventies and even eighties. Not only men and women in the society at large are preparing themselves for a long and healthy life, but also persons with Intellectual Disability (ID) want to live a long life with as little physical difficulties as possible. Unfortunately, because of historical circumstances many persons in the latter group have not had the same opportunities to gain knowledge on successful aging as people in the general population have had. Research shows the overall importance of knowledge as a protective factor that can help a person to age successfully and ways to influence this process.

For many years, persons with ID might not have had the chance to shape their own world, to make their own choices. Many older people with ID - both in the US and in Europe - have lived in large institutions in which choice making was a rare commodity. Thanks to the normalization and integration movement begun in the late sixties and early seventies of the past century many of the old institutions have been closed down and many persons with ID have moved into community dwellings. Within the fabrics of their community most persons with ID now have more opportunities to create a life according to their wishes and choices.

Compared to younger persons with ID, older persons with ID still have only little opportunity to influence their future. When reaching older age, many have lost family members, friends, work, some skills and stamina. They often did not learn to compensate for these losses and plan for later life. The central purpose of this dissertation is to examine the impact of an education program for older adults with ID, called “Person Centered Planning for Later Life: a Curriculum for Adults with Mental Retardation” (Sutton et al., 1994). Theoretical, historical and health notions underlying the program are discussed. The program lasts about four months, with a two-hour lesson each week; it teaches older people with ID the important issues of later life, like how to make choices, the importance of physical exercise and eating healthy foods, possible leisure and recreation activities, how to make new friends and keep old ones, options for early retirement or part-time work, various types of living arrangements, and how to maximize the student’s influence on his or her Individual Service Plan. To make things more concrete two field trips are included in the curriculum: one in connection with the lessons on leisure and recreation activities and one to show participants some possible future living arrangements.

The research questions in both the US and the Netherlands were:
1. What is the impact of training in personal empowerment and later life planning on life satisfaction, leisure and recreation activity, social support resources, and opportunities for daily choice making of adults with ID over a period of six months?
2. What is the impact of this training on knowledge regarding personal choice making and retirement options?

In both research designs intervention and reference groups were planned; in the Netherlands persons in the reference group could attend the course later in the year.

Evaluation done in the US directly after course's end shows a significant increase in the mean curriculum knowledge score for the intervention group over the comparison group, as well as an increase in the amount of choice over time (Heller et al., 2000). There was no significant main effect of life satisfaction over time or significant differences between intervention and comparison groups, although the first slightly increased in life satisfaction and the latter slightly decreased, the differences not being significant.

In the Netherlands evaluation directly after course's end shows a statistically significant gain in participants' knowledge on issues that are close to their personal fields of interest like aging, and choice making. Women, with a mild ID, living independently, made a statistically significant gain in knowledge on “aging” and “choice making”. All participants gained in knowledge on the other issues, but the increase was not statistically significant. In the Netherlands a second evaluation was done three months after course's end. The only issue that remained statistically significant over this period was “choice making”. Knowledge on the other issues decreased; the level of knowledge, however, was still higher than before the course started.

Results show that participants are more satisfied with their leisure time activities after finishing the training. The difference is statistically significant. Within the intervention group men, persons with mild ID and person living independently with support are more satisfied with the activities they can pursue in their free time. On average, persons with moderate ID become less satisfied (this thesis).

The original idea of the authors of the course was to include in the curriculum a part on death, loss and dying. Because of the sensitivity of the subject and because individuals with ID differ greatly with regard to their ability to conceptualize death and dying and in their personal experiences, they decided against it and created a separate program: “Person-Centered Planning for Later Life: Death and Dying - a Curriculum for Older Adults with Intellectual Disabilities” (Sterns et al., 1999). Apart from being an instrument to actually teach persons with ID about death and dying - teaching being the goal of adult education - the course also provides ways and means to help persons with ID to learn to cope with past or present losses.

The program starts with an introduction of the four basic concepts underlying an understanding of death and dying - causality (knowledge of the causes of death), finality (the understanding that all life functions cease with death), inevitability (the understanding that all living things eventually die) and irreversibility (knowledge that, once dead, a deceased person cannot return to life). Later lessons teach participants how they can cope with loss and how to show sympathy to the bereaved family, how to behave during wakes and memorial services and how to plan one's own funeral service. The program closes off with a field trip to a place of participants' choice that has to do with death or dying.

In the US participants show a major increase in knowledge after the course on all four concepts. In the Netherlands participants only show an increase in knowledge on the causes of death; apparently they are quite knowledgeable on the other three concepts and the course teaches them nothing new. In this research design there is no reference group and assessments are only done before and directly after the course.

For the same - historical - reasons not only persons with ID need some training to learn to prepare themselves for later life; persons with chronic mental health problems (CMHP) meet the same obstacles. The curriculum for adults with ID was adapted to suit the interests of persons with CMHP: the curriculum “Later Life Planning for Adults with Mental Retardation”. In the research design to evaluate the effectiveness of the course there is only an intervention group; assessments are done before and directly after the course. In all participants the knowledge in Choice Making and Individual Care Plan Meeting increases statistically significant. On all other themes there is a large difference in outcome between participants with only CMHP and participants with CMHP and intellectual disability: apparently the course appeals more to persons with a dual diagnosis than to persons with “only” chronic mental health problems. Persons with CMHP often performed at the same or even under their baseline measure, while persons with a dual diagnosis showed an increase in knowledge. Before becoming a person with CMHP, participants without ID had a full life within society, were married with children and had regular jobs, and were quite knowledgeable on subjects taught in the curriculum. The course tells them nothing new and some of them dropped out soon after the first lessons. It is therefore clear that without adaptations the course is not useful for persons with CMHP without ID.

This thesis stresses the importance of avoiding disease and disability, the maintenance of a sufficient level of cognitive functioning, and a continuing engagement with life, being the prerequisites for successful aging or aging well (Rowe and Kahn, 1997, 1998). Although aging well is not always within the reach of the individual and depends very much upon the individual’s starting point and future perspective, active involvement in leisure and social activities is essential, together with good health and financial security (Schaie, 1983).
An important aspect in this process is choice making. Exercising choices helps a person to create a successful and productive life (Krain, 1995). The courses “Later Life Planning” teach persons with ID and persons with CMHP how to make choices. Research presented in this thesis indicates that knowledge on choice making remains stable over time, while knowledge on the other themes disappears. Therefore it is advisable that service providers both in the fields of ID and in the field of mental health problems teach their clients how to make choices: through individual change strategies decline and loss can be avoided and people can live a better life, not adding years to life, but life to years.

Maastricht, March 2005

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Curriculum Vitae Maria van Laake

Born in Nijmegen (Netherlands) on the third of April 1948 as the oldest child in a family of three. Her father was head master of an elementary school and her mother was a trained community nurse. After finishing Mariënbosch - a high school for girls only - she started studying Education at Nijmegen University and got married, both in 1969.

Two suns were born in 1973 and 1976 respectively, before she graduated in 1977 as an educator specialized in children with learning disabilities and behavioral problems. By the time a daughter was born in 1980, she was a member of the city counsel in Velsen. Because of this function - and because of personal interests - she became chairperson of the RIAGG Midden Kennemerland (Regional Ambulatory Service for Persons with Mental Health Problems) and of a community center in Oud-IJmuiden. Being a person that always was very much interested in school matters, she became a member of the board of her children's elementary school, a position she held for over ten years. She started working as a school psychologist with the School Advisory Service in Beverwijk in 1984, until the family moved to Maastricht in 1988.

In Maastricht she started working in Vijverdal, a mental hospital. There she got involved in several care innovation projects. The first was a project that promoted a better cooperation and exchange of expertise between the fields of mental illness and intellectual disabilities; the second was a project that offered a "low-threshold" consultation center for parents and children with educational problems; the third project involved creating a regional care circuit for Korsakov patients.

In 1998 she was asked to become a trainer of the curriculum "Later Life Planning for Adults with Mental Retardation". IPSER (Institute for Psycho-Social and Epidemiological Research) and Maastricht University were both engaged in this project which was supervised by dr. Meindert Haveman.

Also in 1998 she became - on a part-time basis and for two years - the interim director of a shelter for abused and run-away women.

In the year 2000 she initiated two spin-off projects from training the curriculum "Later Life Planning". The first is the course "Preparing Adults with ID for Loss, Death and Dying". She translated the original American curriculum in Dutch and taught the course in five different places. The second is "Later Life Planning for Adults with Chronic Mental Health Problems". This course is an adaptation she made of the curriculum "Later Life Planning for Adults with Mental Retardation". The course was presented to five different groups of persons with chronic mental health problems, some of which she knew from the former Vijverdal care innovation project. She did the scientific evaluation of both courses; the results and the outcome of training the three curricula are presented in this thesis.

Word of gratitude

If my parents would have lived, I know they would have been very proud of me today. But helas, they are both long dead and hopefully happy together in the Heaven they both believed in so deeply.

My children are also very proud - they made an e-mail account with "Doctor Mother" in the address, so that is okay too. They did not suffer much because their mother was working so hard - they are accustomed to it and besides, they live or have lived all over the world and are or were happily out of the way. Which is a very comforting thought for a mother.

The persons to whom I owe most are Meindert Haveman and René Reijnders. Meindert I met back in 1990 when he agreed to do the scientific evaluation of an innovative care project meant to promote exchange of knowledge and expertise between the fields of mental illness and intellectual disability: "Casemanagement op het grensgebied van psychiatrie en de zorg voor mensen met een verstandelijke handicap". I was working in Vijverdal, a psychiatric hospital, and he was working at the then Epidemiology Department of the then Rijksuniversiteit Limburg, now Maastricht University.

Meindert and I met again in 1997 when he was looking for some knowledgeable trainers to teach the curriculum "Later Life Planning for Adults with Mental Retardation". I got more and more involved in the project and by mid 1998 René Reijnders, Thea Gorissen (our secretary) and I were a team working closely together under Meindert's supervision. Thea put all collected data in computer files and René worked hard to make statistical sense out of it. In 2000 René and Thea had to leave the project, but René remained a loyal friend to whom I have often turned in times of "statistical stress". He and his wife Tiny always offered me a warm cup of coffee and enough comfort to go on again.
This same comfort was also given by Heleen, Meindert's wife. I often invaded on her privacy both during the day and in the evening and always left strong enough to face again my thesis-to-be.

Meindert is not only my "Doktor Fater", but since long he has been a good friend and a strong promoter of my scientific endeavors. With an endless patience he corrected the drafts of the chapters of this PhD study - always by hand, never in a computer file - and pushed me to present my data on various conferences all over the world, from Seattle to Tokyo. He advised me to become a member of the organizations in the field of ID that matter: the AAMR (American Association of Mental Retardation) and the IASSID (International Association of the Scientific Study of Intellectual Disability).

My "Doktor Mutter" dr. Tamar Heller, I met for the first time in 1997 when she introduced the curriculum "Later Life Planning for Adults with Mental Retardation" to the trainers in the Netherlands. She invited me in 2002 at a conference in Dublin to write a PhD study on all the material that was collected before and after the various courses. She gave very valuable - and valued - feed-back on my writings and even - as if this would go without saying - corrected my English. I thank her deeply for her support and enthusiasm without which I would never have started and probably never

would have finished.
Over the years a "ladies group" has emerged out of the conference meetings: Kathy Service, Sunny Kalsy, Heather Wilkinson and Christine Bigby, ladies who together encompass the whole world. Apart from good fun, they offer role models and give inspiration. Especially Heather and Christine - Heather invited us to come to a conference in Newcastle last December where Christine presented research that fitted like a lid on the pot of my thesis. Thank you Christine.

I would also like to thank Detlef Petry, psychiatrist of Vijverdal. I came to work in the psychiatric hospital as an educator, familiar with adolescents and children, but not with adult psychiatric patients, and certainly not with persons with chronic mental illness and intellectual disability. Detlef taught me to respect these people without any prejudice or any holding back, in other words how to engage in a mutual rewarding relationship between burgers of Maastricht.

A word of gratitude is also in place for Jim van Os and all the people from "Sociale Psychiatrie" the department of Maastricht University where I could work and study in a very stimulating and rewarding atmosphere.

The last words are for all my "old friends" who practice every day the paradigm presented in this thesis of "aging well". They are all (or almost all) over eighty years old, they live on different sides of the earth and some did even fight each other during World War II. But they survived and became friends during ski-holidays where I met them years later; together we spent many glorious holidays in the Dolomites. Next year again in Armentarola!

My other old friends live in the US. Back in 1969 I learned their children Dutch - and they learned me English in return. Everyday English that is, not the English of Shakespeare or Milton I learned in school. Over the last years - thanks to AAMR and IASSID conferences - I often stayed in their house in Westboro either on the way in or on the way out.

I do hope that my friends - old and young(er) alike - will be around for a long time. There is so much fun to share together.

Maria van Laake

Appendix I

ONDERZOEKSPROJECT

“OUDERDOMSPLANNING VOOR MENSEN MET EEN VERSTANDELIJKE HANDICAP”

VRAGENLIJST KENNIS

Naam:				
Instelling:				

Met nadruk willen we er op wijzen dat alle gegevens uit deze vragenlijst strikt vertrouwelijk worden behandeld. Bij de terug-rapportage van de resultaten van het onderzoek worden alleen de algemene onderzoeksresultaten gepresenteerd (dus geen individuele resultaten).

Na invulling van de vragenlijst dient dit voorblad te worden verwijderd om de anonimiteit van betrokkene te waarborgen.

ORIGINELE TITEL:
LATER LIFE PLANNING INVENTORY FOR OLDER PERSONS WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES
UIC The University of Illinois at Chicago, Institute for Life-Span Development and

Gerontology, The University of Akron

Drs RJHM Reijnders, Dr MJ Haveman, Drs. M.I.L.L.van Laake

ID GGGG

Datum ....

Duur interview ....

KEUZES MAKEN

1. Kunt u twee keuzes noemen die u deze week heeft gemaakt?
   2 - twee keuzes genoemd
   1 - één keuze genoemd
   0 - geen keuze genoemd

2. Kunt u twee keuzes noemen die u wel zou willen maken, maar die u nu nog niet gemaakt heeft?
   2 - twee voorbeelden genoemd
   1 - één voorbeeld genoemd
   0 - geen voorbeeld genoemd

3. Kunt u twee rechten noemen die u heeft?
   2 - twee rechten genoemd
   1 - één recht genoemd
   0 - geen recht genoemd

4. Wie is volgens u de belangrijkste persoon om aan te denken als u een keuze maakt?
   2 - mijzelf
   0 - een ander

LICHAMELIJKE VERANDERINGEN

5. Kunt u twee manieren noemen waarop uw lichaam verandert als u ouder wordt?

2 - bijvoorbeeld: grijs haar, problemen met zien, horen, lopen
1 - één van de lijst
0 - geen, of irrelevant antwoord

6. Wat zijn twee lichamelijke problemen die mensen kunnen krijgen als ze ouder worden?

2 - bijvoorbeeld: hartziekte, diabetes, osteoporosis, artritis, geheugenproblemen
1 - één van de lijst
0 - geen, of irrelevant antwoord

LICHAAMSBEWEGING

7. Doet de persoon op deze foto wel of niet aan lichaamsbeweging?

{Laat achtereenvolgens de foto zien van een persoon die lichamelijke oefening doet en de foto van een persoon die aan het eten is}

2 - beide correct
1 - één correct
0 - geen correct

8. Welke twee goede dingen gebeuren er met u als u aan lichaamsbeweging doet?
   - **2** - een antwoord dat aangeeft: je fitter voelen, gewichtscontrole, je goed voelen, meer energie hebben, minder spanningen, meer plezier, je hart wordt sterker
   - **1** - één antwoord
   - **0** - geen correct of irrelevant antwoord

9. Denk aan een sport die u graag zou willen beoefenen (bijv. joggen, zwemmen) en doe voor (of vertel) welke beweging(en) bij deze sport horen.
   - **2** - vertellen en uitbeelden
   - **1** - noemt één maar is niet in staat dit uit te beelden of uit te leggen
   - **0** - geen correct of irrelevant antwoord

10. Zijn dit de goede of de verkeerde kleren die men draagt als men aan lichaamsbeweging doet?
    {laat de foto zien iemand in uitgaanskleding en van iemand in sportkleren}
    - **2** - beide correct
    - **1** - één correct
    - **0** - geen correct

11. Noem twee dingen die u moet doen voor u met sporten begint
    - **2** - bijv. twee van de volgende: warming-up, toestemming van de dokter, langzaam beginnen
    - **1** - één van de lijst
    - **0** - irrelevant antwoord - ‘Ik hou van lichamelijke oefening’

VRIJE TIJD

12. Wat is vrije tijd?

1 - tijd waarin ik doe wat ik wil, lezen, TV kijken, bingo etc.

0 - geen correct of irrelevant antwoord

13. Waarom is het goed om vrije tijd te hebben?

2 - dan blijf je bezig, interessante dingen doen, naar plaatsen gaan die je niet kent

1 - niet werken, rondhangen

0 - geen correct of irrelevant antwoord

14. Noem twee vrijetijdsactiviteiten die u alleen kunt doen.

2 - handwerken, verzameling aanleggen, etc.

1 - één van de lijst

0 - geen correct of irrelevant antwoord

15. Noem twee vrijetijdsactiviteiten die u in een groep kunt doen.

2 - kaartspelen, sporten, sociale activiteiten, dansen etc.

1 - één van de lijst

0 - niets of iets individueels

16. Noem twee plaatsen waar u vrijetijdsactiviteiten kunt doen.

2 - dienstencentrum, thuis, religieuze organisaties of een andere relevante plaats

1 - één van de lijst

0 - noemt alleen iets dat hij/zij leuk vindt, geen correct antwoord

17. Noem twee dingen die iemand in zijn vrije tijd kan verzamelen om daarmee een verzameling aan te leggen.
    2 - twee goede items
    1 - één goed item
    0 - geen

18. Noem twee redenen waarom het leuk is om dingen te verzamelen / om een verzameling te hebben.
    2 - je interesseert je ergens voor, je kunt je interesse met anderen delen, je kunt erover praten, je kunt er naar uit kijken.
    1 - één van de lijst
    0 - irrelevant antwoord, bijv. “Ik kijk TV”

WERK

19. Wat betekent ‘fulltime’ werken?
    1 - elke dag werken, 38 uur per week
    0 - geen correct of irrelevant antwoord

20. Wat betekent ‘parttime’ werken?
    1 - niet elke dag werken, halve dagen werken, elke dag een beetje werken
    0 - geen correct of irrelevant antwoord

21. Wat betekent het woord ‘pensioen’?
    1 - niet meer hoeven werken, meer vrije tijd hebben, niet naar het werk hoeven te gaan, niet betaald krijgen
    0 - geen correct of irrelevant antwoord

22. Wat zijn twee redenen waarom iemand niet wil werken?

2 - wil een andere activiteit doen, genoeg hebben van het werk, tijd om te rusten, problemen op het werk

1 - één van de lijst

0 - geen of irrelevant antwoord

23. Wat zijn twee redenen waarom iemand wèl wil werken?

2 - geld nodig hebben, om actief te blijven, goed te voelen over hetgeen je doet, niet te oud om te leren, vrienden maken op het werk

1 - één van de lijst

0 - geen of irrelevant antwoord

24. Als u ouder wordt, waarom zou u dan niet meer kunnen werken?

2 - ziek zijn, geen vervoer hebben, geen plaats om te werken, er zijn geen banen voor oudere mensen

1 - één van de lijst

0 - geen of irrelevant antwoord

WONEN

25. Noem eens twee plaatsen waar mensen kunnen wonen?

2 - thuis, bij familie, in een socio-woning, begeleid zelfstandig wonen, in een sociaal pension

1 - één van de lijst

0 - geen of irrelevant antwoord

26. Wat zijn twee dingen die je moet delen als je met andere mensen samen woont?
    2 - het huishouden, de woonkamer, het eten, TV etc.
    1 - één van de lijst
    0 - geen of irrelevant antwoord

DE BESPREKING VAN HET BEGELEIDINGSPLAN

27. Tijdens de bespreking van het begeleidingsplan (noem de term die gebruikelijk is binnen de voorziening) wordt van u verwacht dat
    2 - u zelf zegt wat u wil dat er verder met u gaat gebeuren
    0 - u luistert en u laat de staf het meeste zeggen

28. Wat is een **doel**?
    2 - iets dat u voor uzelf wilt
    0 - een regel die zegt wat u moet doen

Appendix II

ONDERZOEKSPROJECT

“OUDERDOMSPLANNING VOOR MENSEN MET EEN VERSTANDELIJKE HANDICAP”

VRAGENLIJST GEDRAG EN ATTITUDE

Naam:				
Instelling:				

Met nadruk willen we er op wijzen dat alle gegevens uit deze vragenlijst strikt vertrouwelijk worden behandeld. Bij de terug-rapportage van de resultaten van het onderzoek worden alleen de algemene onderzoeksresultaten gepresenteerd (dus geen individuele resultaten).

Na invulling van de vragenlijst dient dit voorblad te worden verwijderd om de anonimiteit van betrokkene te waarborgen.

ORIGINELE TITEL:

LATER LIFE PLANNING CURRICULUM PRE-TEST/POST-TEST FOR OLDER PERSONS WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES.
UIC The University of Illinois at Chicago, Institute for Life-Span Development and

Gerontology, The University of Akron

Drs RJHM Reijnders, Dr MJ Haveman, Drs. M.I.L.L. van Laake

ID GGGG

Datum ....

Duur interview ....

IK GA U EEN AANTAL VRAGEN STELLEN OVER UW LEVEN. IK ZAL U VRAGEN HOE U ZICH VOELT, WAT U GRAAG WILT DOEN, OVER UW WERK, HOE U WOONT EN OVER UW VRIENDEN. ER ZIJN GEEN GOEDE OF SLECHTE ANTWOORDEN. WIJ WILLEN ALLEEN WETEN WAT U VAN UW LEVEN VINDT EN WAT U GRAAG WILT DAT ER GEBEURT.

Sectie A: RECREATIE EN VRIJETIJDSACTIVITEITEN

1. Welke dingen doet u nu voor uw plezier?

2. Welke dingen zou u voor uw plezier willen doen die u nu nog niet doet?

3. Bent u tevreden of niet tevreden met de dingen die u in uw vrije tijd doet?

Tevreden.. **2**

Niet tevreden... **1**

Geen van beiden... **0**

4. Heeft u genoeg dingen te doen in uw vrije tijd of doet u niet genoeg dingen in uw vrije tijd?

Genoeg dingen te doen................................ **2**

Niet genoeg dingen te doen........................... **1**

Geen van beiden...................................... **0**

IK GA U NU EEN AANTAL DINGEN VRAGEN DIE MENSEN KUNNEN DOEN. IK WIL GRAAG WETEN WELK VAN DEZE DINGEN **U** DOET.

5a. Doet u dit?	**NEE**	**JA**	**5b.** Zo nee, zou u dit willen doen?	
			NEE	**JA**
1. reizen	0	1	0	1
2. zingen	0	1	0	1
3. lezen	0	1	0	1
4. TV kijken	0	1	0	1
5. muziek luisteren	0	1	0	1
6. tuinieren	0	1	0	1
7. cursus volgen	0	1	0	1
8. ontspannen	0	1	0	1

9. zwemmen	0	1	0	1
10. muziekinstrument bespelen	0	1	0	1
11. winkelen	0	1	0	1
12. werken met gereedschap	0	1	0	1
13. fotograferen	0	1	0	1
14. dansen	0	1	0	1
15. naaien, handwerken	0	1	0	1
16. kaarten	0	1	0	1
17. uitgaan	0	1	0	1
18. seniorencentrum bezoeken	0	1	0	1
19. paardrijden	0	1	0	1
20. bowlen	0	1	0	1
21. koken/bakken voor plezier	0	1	0	1
22. huisdieren verzorgen	0	1	0	1
23. tafeltennis	0	1	0	1
24. gewoon tennis	0	1	0	1
25. voetballen	0	1	0	1
26. wandeltocht maken	0	1	0	1

27. pottenbakken	0	1	0	1
28. museum bezoeken	0	1	0	1
29. schouwburg bezoeken	0	1	0	1
30. joggen	0	1	0	1
31. vissen	0	1	0	1
32. naar voetbalwedstrijd gaan	0	1	0	1
33. dingen verzamelen	0	1	0	1
34. boottocht maken	0	1	0	1
35. uit eten gaan	0	1	0	1
36. fietsen	0	1	0	1
37. midgetgolf	0	1	0	1
38. naar feestjes gaan	0	1	0	1
39. picknicken	0	1	0	1
40. vrijwilligerswerk doen	0	1	0	1
41. naar een concert gaan	0	1	0	1
42. een kerk bezoeken	0	1	0	1
43. familie/kennissen bezoeken	0	1	0	1
44. schaatsen	0	1	0	1

45. bewegen om fit te blijven	0	1	0	1
46. biljarten	0	1	0	1
47. schilderen	0	1	0	1
48. kamperen	0	1	0	1

NU GA IK U IETS VRAGEN OVER UW GEZONDHEID

Sectie B: GEZONDHEID EN WELZIJN

1. a) Wat doet u om gezond te blijven (lichamelijk goed/niet ziek te voelen)?

b) Wat eet u (of wat eet u niet) om gezond te blijven?

c) Wat wilt u veranderen aan wat u eet?

2. a) Welke lichaamsbeweging doet u nu om gezond te blijven?

b) Welke lichaamsbeweging zou u willen doen die u nu niet doet?

3. Vindt u hetgeen u nu eet gezond of niet gezond?

Gezond..	**2**
Niet gezond.. .	**1**
Geen of beiden..	**0**

4. Heeft u genoeg beweging of niet genoeg?

Genoeg beweging.......................................	**2**
Niet genoeg beweging..................................	**1**
Geen of beiden..	**0**

NU GAAN WE PRATEN OVER UW WERK

Sectie C: WERK EN PENSIOEN

1. Wat voor een soort werk doet u nu?

2. Wilt u dit werk wel of niet blijven doen?

Werk blijven doen.................................	**2**
Werk niet blijven doen............................	**1**
Geen of beiden....................................	**0**

3. Wat zou u willen veranderen aan uw werk?

4. a) Is er ander werk dat u liever zou doen?

Ja..	**1**
Nee...	**0**

b) Wat voor een werk zou dat dan zijn?

5. Hoe tevreden bent u met .... [een van de volgende zaken]

werkomstandigheden	**tevreden**	**niet tevreden**	**geen/beide**
hoeveelheid geld	2	1	0
het soort werk	2	1	0
uw baas	2	1	0
collega’s	2	1	0

6. a) Zou u wel of niet met pensioen willen (minder werken of helemaal niet)

Met pensioen................................ **2**
Niet met pensioen........................... **1**
Geen of beiden.............................. **0**

b) Zo JA, wilt u dan minder werken of helemaal niet meer?

Minder werken............................... **1**
Helemaal niet meer werken................... **0**

c) Hoe zou u uw tijd dan besteden?

NU GAAN WE PRATEN OVER DE MANIER WAAROP U LEEFT

Sectie D: WOONSITUATIES

1. Waar woont u nu?.................................. **1**
Bij mijn familie (eigen of pleeggezin)................ **2**
Begeleid Zelfstandig Wonen (1-2 pers + hulpverl)...... **3**
Kleine sociowoning (3-15 pers + hulpverl)............. **4**
Grote sociowoning (> 15 pers + hulpverl).............. **5**
Gezins Vervangend Tehuis.......................... **6**
Afdeling (intramuraal)............................... **7**
Geheel zelfstandig.... .... **8**
Anders namelijk

2. Bevalt het u waar u woont of bevalt het u niet?

Het bevalt	**2**
Het bevalt niet	**1**
Geen of beiden	**0**

3. a) Wilt u liever ergens anders wonen of wilt u blijven waar u nu woont?

Liever ergens anders	**2**
Liever niet ergens anders	**1**
Geen of beiden	**0**

b) Zo JA, waar zou u dan willen wonen?

Bij mijn familie (eigen of pleeggezin)	**1**
Begeleid Zelfstandig Wonen (1-2 pers + hulpverl)	**2**
Kleine sociowoning (3-15 pers + hulpverl)	**3**
Grote sociowoning (> 15 pers + hulpverl)	**4**
Gezins Vervangend Tehuis	**5**
Afdeling (intramuraal	**6**
Geheel zelfstandig	**7**
Anders namelijk	

c) Wat zou u willen leren om ergens anders te kunnen wonen?

Hoe tevreden bent u waar u nu woont met de volgende zaken:

	tevreden	**niet tevreden**	**geen/beide**
het eten	2	1	0
de omgeving	2	1	0
medebewoners	2	1	0
hoe het er uit ziet	2	1	0
regels (wat wel en niet mag)	2	1	0

5. Wat zou u willen veranderen aan de plaats waar u nu woont?

6. DAGELIJKSE KEUZE LIJST

kiest uzelf of iemand anders	zelf	een ander	familie	vriend	staf
wat u eet?	1	0	1	1	1
Welke kleren u draagt?	1	0	1	1	1
welke dingen u doet in de vrije tijd?	1	0	1	1	1
welke TV programma’s u kijkt?	1	0	1	1	1
Hoe u uw geld uitgeeft?	1	0	1	1	1
wanneer u met vrienden uit gaat?	1	0	1	1	1
hoe laat u naar bed gaat?	1	0	1	1	1
hoe u uw kamer inricht?	1	0	1	1	1
wanneer u uw kamer schoonmaakt?	1	0	1	1	1
wanneer u bezoek krijgt?	1	0	1	1	1
welk werk u moet doen?	1	0	1	1	1

met wie u samen woont?	1	0	1	1	1

Als respondent 'een ander' noemt in tweede kolom aangeven wie keuze maakt.(met **vriend** wordt ook **medebewoner** bedoeld**)**

Sectie E: ONDERSTEUNEND NETWERK INDEX

1. Nu ga ik u vragen hoe tevreden u bent met de hulp die u van andere mensen krijgt.

	tevreden	**niet tevreden**	**geen/beide**
ouders	2	1	0
andere familieleden	2	1	0
vrienden	2	1	0
staf	2	1	0

2. Nu ga ik u vragen wat andere mensen voor u doen als u hier behoefte aan heeft.

Per vraag aangeven wie het zijn en hoeveel personen. Indien geen hulp wordt geboden 0 invullen.

	hoeveel personen helpen?			
	Ouders	familie	vrienden	staf
wie helpt als u zich gespannen voelt?				
wie helpt om voor u te zorgen?				
wie helpt met onderhoud van het huis?				
wie voorkomt dat u zich eenzaam voelt?				
wie geeft u geld en koopt dingen die u nodig heeft?[excl werkgever]				
met wie maakt u plezier?				
met wie praat u als u keuzes moet maken?				
wie helpt u doelen te maken (plannen van dingen)?				
wie helpt u aan de voorzieningen die u nodig heeft?				

Appendix III

Demografische vragenlijst onderzoeksproject
"Ouderdomsplanning voor mensen met een verstandelijke handicap"

Onderzoeksnummer:			
Periode:		groep:	
datum:			

DEEL A
In het eerste deel van de vragenlijst staan algemene vragen over betrokkene.

1. **Wat is de leeftijd?**
☐ jaar oud (leeftijd invullen)

2. **Wat is het geslacht?**
1 man
2 vrouw

3. **Verstandelijk niveau van functioneren?**
1 licht (IQ 52-70)
2 matig (IQ 36-51
3 ernstig (IQ 20-35)
4 onbekend

4. **Primaire vorm van communiceren?**
(meerdere antwoorden mogelijk)
1 geen
2 aanwijzen
3 praten
4 teken-/gebarentaal
5 symboolsystemen (Bliss, etc)
6 anders:

DEEL B
In deel B worden vragen gesteld over de actuele woonsituatie.

1. Actuele woonsituatie
1 bij de ouders of familieleden
2 pleeggezin
3 zelfstandig in eigen huis of huurhuis
4 begeleid wonen
5 pension (kamer en maaltijd zonder personele ondersteuning)
6 sociowoning of dependance van gezinsvervangend tehuis (GVT)
7a woongroep internaat of GVT waarbij begeleiding en zorg binnen de instelling wordt aangeboden
7b aantal bewoners: ☐
8 woongroep internaat of GVT waarbij begeleiding en zorg vooral buiten de instelling wordt aangeboden
9 overgangsverblijf tussen woongroep en verpleeghuis
10 verpleeghuis
11 afdeling van internaat
12 overige:
13 geen op handen zijnde verandering in de actuele woonsituatie

DEEL C
Het derde en tevens laatste deel van de vragenlijst gaat over dagelijkse activiteiten, sociale- en vrijetijdsbesteding.

1. Actuele dagbesteding

(meerdere antwoorden mogelijk)
1 geen gestructureerd dagprogramma buitenshuis
2 regelmatig terugkerende vrijwilligersactiviteiten buitenshuis

3
school:

4 dagopvang
5 dag activiteitencentrum (individuele, sociale- en beroepsvoorbereidende activiteiten)
6 arbeid/werk trainingscentrum (sociale- en beroepstraining)
7 WSW voorziening
8 begeleid werk op de vrije arbeidsmarkt
9 zelfstandig werken op de vrije markt zonder specifieke begeleiding

10
anders:

11 geen wijzigingen in de actuele woonsituatie in het vooruitzicht of aanbevolen

2. Sociale en vrijetijdsaktiviteteiten gedurende de laatste maanden

(meerdere antwoorden mogelijk)

1 geen enkele activiteiten
2 telefoneerde met familieleden of vrienden
3 ging bij familieleden op bezoek
4 ging bij vrienden of buren op bezoek
5 deed inkopen of ging uit eten (alleen of met anderen)
6 ging naar sociale- en/of vrijetijdsactiviteiten buitenshuis
7 was betrokken bij hobby- en/of individuele vrijetijdsactiviteiten

8
anders:

3. Factoren die deelname aan sociale activiteiten belemmeren

(meerdere antwoorden mogelijk)

1 geen factoren
2 gebrek aan interesse
3 geen begeleiding aanwezig
4 geen vervoersmogelijkheden aanwezig
5 geldgebrek
6 problemen met de gezondheid
7 aanwezigheid gedragsproblemen

8
anders:

Eventuele opmerkingen:

Appendix IV

DEELNEMERSFORMULIER

IK DOE MEE AAN DE CURSUS

‘LEVENSPLANNING VOOR MENSEN MET EEN VERSTANDELIJKE BEPERKING’.

IK GEEF TOESTEMMING OM MEE TE DOEN AAN HET BIJ DE CURSUS HORENDE ONDERZOEK VAN DE UNIVERSITEIT MAASTRICHT.

IK GEEF OOK TOESTEMMING AAN DE UNIVERSITEIT MAASTRICHT OM MIJN GEGEVENS TE GEBRUIKEN VOOR HET ONDERZOEK.

IK ZELF KAN BEPALEN MET HET ONDERZOEK TE STOPPEN.

ALS IK DE CURSUS AFMAAK, KRIJG IK EEN DIPLOMA.

NAAM	HANDTEKENING
☐.......................………………	☐..............………………..........

Appendix V

TOESTEMMINGSFORMULIER

De vertegenwoordig(st)er van:

Naam: ....

Geboortedatum: ....

Adres: ....

Geeft hierbij toestemming dat bovengenoemde persoon mee doet aan de cursus
'Levensplanning voor mensen met een verstandelijke beperking'
en deelneemt aan het onderzoek van de Universiteit van Maastricht dat bij deze
cursus hoort.

Datum	Plaats ....

Naam	Adres	Handtekening
........…........................	.........….........................	.........…..........................

Appendix VI

VRAGENLIJST
“Kennis en begrip van dood, sterven en verlies”

Maria van Laake
René Reijnders
Meindert Haveman

Juli 2000

IPSER/Universiteit Maastricht

Vragenlijst “Kennis en begrip van dood, sterven en verlies”

1 Ken je iemand die is doodgegaan? Wat vond je daar toen van?
2a Heb je allebei je ouders nog? ☐ Ja ☐ Nee
2b Welke ouder leeft nog? ☐ Vader ☐ Moeder
3 Heb je vrienden of medebewoners verloren? ☐ Ja ☐ Nee

4 Wat gebeurt er met het lichaam van een mens als hij dood gaat? (uitleg als: het hart houdt op met kloppen; je houdt op met ademen; organen doen het niet meer; enz.)

5 Waar gaat een mens naar toe als hij gestorven is?

6 Waardoor gaat een mens dood (ouderdom, ziekte, ongelukken)?

7 Bestaan er mensen die niet dood gaan?

8 Wat denk je, sterven alleen oude mensen of gaan er ook jonge mensen dood?

9 Kunnen mensen die al gestorven zijn weer levend worden?

10 Ben je bang voor de dood?

11 Wat gebeurt er met een mens die gestorven is?

12 Hoe voel je je als er iemand dood gaat die je goed gekend hebt (uitingen van verdriet / bedroefdheid beschrijven)?

13 Hoe laat je zien dat je mee leeft met een persoon die net iemand verloren heeft waar hij of zij heel veel van hield?

14 Ben je al eens op een begrafenis geweest? ☐ Ja ☐ Nee

15 Wat gebeurt er op een begrafenis?

16 Hoe weet je wat er bij een begrafenis gebeurt (TV, vrienden, begeleiders, enz)?

17 Ben je al eens eerder op een begraafplaats / kerkhof geweest?
☐ Ja ☐ Nee

18 Waarvoor zijn er begraafplaatsen?

19 Hoe verdrietig ben je?

a.	als je huisdier doodgaat	1	2	3
b.	als er een vriend van je dood gaat	1	2	3
c.	als jij je lievelingsspulletjes kwijt bent geraakt	1	2	3
d.	als je met een goede vriend ruzie hebt gehad	1	2	3

eventuele opmerkingen/toelichting

Naam:

Plaats van onderzoek:

Biografische belangrijke gebeurtenissen (bijzondere rouwervaringen)?
Vergelijk: ervaringen waarover tijdens de cursus wordt gesproken en ervaringen die de begeleiders bekend zijn.

Appendix VII

DEELNEMERSFORMULIER

IK DOE MEE AAN DE CURSUS

‘LEVENSPLANNING VOOR LANGDURIG ZORGAFHANKELIJKE CLIËNTEN IN DE GEESTELIJKE GEZONDHEIDSZORG’.

IK GEEF TOESTEMMING OM MEE TE DOEN AAN HET BIJ DE CURSUS HORENDE ONDERZOEK VAN DE UNIVERSITEIT MAASTRICHT.

IK GEEF OOK TOESTEMMING AAN DE UNIVERSITEIT MAASTRICHT OM MIJN GEGEVENS TE GEBRUIKEN VOOR HET ONDERZOEK.
DIT HEEFT VOOR MIJ ALS PERSOON GEEN VERDERE GEVOLGEN.

IK ZELF KAN BEPALEN MET HET ONDERZOEK TE STOPPEN.

ALS IK DE CURSUS AFMAAK, KRIJG IK EEN DIPLOMA.

NAAM	HANDTEKENING
☐..............……………………..........	☐..............……………………..........

Appendix VIII

TOESTEMMINGSFORMULIER

De vertegenwoordig(st)er van:

Naam: ....

Geboortedatum: ....

Adres: ....

Geeft hierbij toestemming dat bovengenoemde persoon mee doet aan de cursus ‘Ouderdomsplanning voor langdurig zorgafhankelijke cliënten in de geestelijke gezondheidszorg’
en deelneemt aan het onderzoek van de Universiteit van Maastricht dat bij deze cursus hoort.

Datum ....

Plaats ....

Naam	Adres	Handtekening
........……........................	.........…….........................	.........…….........................