TRIADE 2.0

AGEING AND INTELLECTUAL DISABILITY: **GUIDE TO QUALITY OF LIFE AND INCLUSIVE PRACTICES**

Workbook for course designers and trainers

Triade 2.0

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General introduction to the TRIADE 2.0 project

TRIADE 2.0 is a project on "Cooperation for innovation and the exchange of good practices", developed under the key action of adult education of the ERASMUS+ programme. The strategic partnership is formed by 9 partners from Belgium, Bulgaria, Italy, Slovenia and Spain.

TRIADE 2.0 tackles the challenge of improving the social inclusion and quality of life of a new segment of population: ageing adults with intellectual disabilities (hereafter AAWID). In order to improve the competences of AAWID and the professionals providing support to them, the project has developed three sets of training materials:

1) My new inclusive job": training toolkit for educators of AAWID. This toolkit is formed in turn by 4 outputs:

    a. **A WORKBOOK FOR TRAINERS (presented in this document)**
    b. A workbook for educators.
    c. PowerPoint classroom presentations.
    d. MOOC course (Massive Open Online Course).

2) "My New Ageing Me": MNAM Interactive Training Platform formed by 2 outputs:

    a. 50 inspiring exercises and a set of resources to get the most out of the exercises.
    b. Educators platform guidelines: Validation methodology of the platform, how to transfer the competences and how to develop accessible content.

3) Training plan: TRIADE 2.0 master plan where it is explained the "what, where, when and how" details of the project training and learning activities.

This workbook “Ageing and disability: a guide on quality of life and inclusive practices (workbook for trainers)” is divided into two parts:

1. 4 didactic units with content related to ageing, intellectual disability and how to navigate through TRIADE 2.0 training platform (MNAM):

    Unit 1: The ageing process.
    Unit 2: Impact of ageing on QoL of AAWID.
    Unit 3: Methodology working on QoL with AAWID.
    Unit 4: The MNAM interactive training platform.

2. A Training pedagogical resources guide to build a 25-hour face-to-face training course.

The two primary target groups of this Workbook are **course developers and trainers** who are responsible to design vocational training courses and teaching in the fields of aging or disability. In addition, the first part of this workbook can be used as a self-study book by the learners of the 25-hour course.

The first part of the workbook is formed by 4 didactic units. The first three units consist of theoretical and practical content, and exercises based principally on the **Quality of Life Model** (Schalock and Verdugo) and its domains, as well as to the **social inclusion dimension**. The developed training content of the unit I, II and III deal with the following topics: a) ageing (theories and determinants of ageing, ageism, frailty, resilience..); and b) intellectual disability (concept and dimensions of Quality of life, impact of ageing in people with disabilities, the person-centred planning, individual support plan, planning the future and working with AAWID...). In addition, unit IV is aimed at helping educators on how to use the TRIADE 2.0 MNAM interactive training platform exercises as an additional pedagogical tool to improve the quality of life of AAWID.

The second part of the workbook is a training pedagogical resources guide to help training developers and trainers to plan, implement and evaluate a 25-hour face-to-face training action based on the workbook content. The training outcomes (knowledge, skills and competences) expected to be achieved in the training course are fully explained according to the European Qualification Framework (EQF), having been developed to achieve the level 6 of this framework. The target group of this training course (learners) would be those educators and front-line professionals (caregivers, social workers, psychologists, occupational therapists...) who give support to ageing adults in elderly and disability services.

Finally, this workbook is aligned and complementary to the other TRIADE 2.0 training materials whose features are summarized in the following table and can freely be downloaded from TRIADE 2.0 website: https://www.ivass.gva.es/Triade2.html.

Table 0-1: Map to TRIADE 2.0 training materials and intellectual outputs.

Name	Features	Target groups (disability and elderly services)	Languages
Ageing and disability: a guide to quality of life and inclusive practices. (Workbook for trainers)	**Two parts:** **1. Knowledge content and exercises to improve the quality of life of ageing adults with intellectual disabilities.** **2. Pedagogical Guide to implement a 25-hour face-to-face course with the content developed in part 1.**	• **Training course designers.** • **Training coordinators.** • **Trainers.**	• **Bulgarian.** • **Flemish.** • **Italian.** • **Slovenian.** • **Spanish.**
Ageing and disability: a guide to quality of life and inclusive practices. (Workbook for educators)	Knowledge content and exercises to improve the quality of life of AAWID. (Same content as part 1 of the "AAWID: Workbook for trainers"). This is the training material to be used by learners during the 25-hour course or as self-study book.	• Educators. • Care-givers. • Social workers. • Occupational therapists. • Psychologists.	• Bulgarian. • Flemish. • Italian. • Slovenian. • Spanish.
Classroom presentations	• Theoretical content presentations (PowerPoint or PDF) used by the trainers when implementing the 25-hour course. • Practical content presentations (PowerPoint or PDF) used by the trainers when implementing the 25-hour course.	• Trainers of the 25-hour course. • Learners of the 25-hour course.	• Bulgarian. • Flemish. • Italian. • Slovenian. • Spanish.
MOOC (Massive open online course)	Video lessons and other resource based on the workbook for trainers to take part as a learner in a mini-online course.	• Educators. • Care-givers. • Social workers. • Occupational therapists. • Psychologists.	• English.
MNAM: Interactive training platform.	• 50 inspiring exercises and instructions to be used by educators together with AAWID to improve their quality of life and social inclusion. • Complementary pedagogical resources to get the most of the exercises: exercises validation methodology, how to develop accessible exercises, and how to transfer the competences to the daily life activities.	• Educators. • Ageing adults with intellectual disabilities.	• Bulgarian. • Flemish. • Italian. • Slovenian. • Spanish.
Educators platform guidelines	Printable version of the exercises, tools and pedagogical resources included in the platform.	• Educators. • Ageing adults with intellectual disabilities.	• Bulgarian. • Flemish. • Italian. • Slovenian. • Spanish.
2.0 Training plan	TRIADE 2.0 master plan where it is explained the "what, where, when and how" details of the project training and learning activities.	• Training coordinators. • Course designers.	• English.

Introduction to the Workbook for trainers

Professionals supporting ageing people in services for the elderly and services for disabled people are challenged in several ways. Their competences - skills and attitudes – don't match any longer the expectations of the 'ageing' person, the societal challenges, the organizational, regional, national and European policies. The training as presented in this workbook is a necessary step to narrow the gap. It is not a sufficient step to work with the professionals to gain insight in the new expectations, as also organizations, government and the social environment/society need to change their (HR, quality, …) policies and perceptions on ageing and ageing people.

Persons with disabilities in Europe today are living longer and in better health conditions thanks to positive developments in health treatment and societal achievements. In addition, people generally are living longer, and so many will acquire disabilities as part of that longevity. This may invite to invest more and more in disability or medical oriented support and care approaches, but : these approaches don't recognize the expectations of the ageing person to feel well, to be well, to contribute, to have a say. A holistic approach, taking into consideration all these domains, and not only the physical one, is expected. Quality of Life may be the leading model to develop such an approach.

Society is increasingly appreciating the contribution which older people can make, although some challenges still have to be overcome.

Narrowing the gap by offering the professionals a training to acquire insight in the new approach (the holistic QOL-model) is the main goal of the workbook. What are the changing support needs and expectations of the ageing person, what is the nature of the 'quality of life' of the ageing person with and without disabilities and what are critical methodologies to work toward wellbeing of ageing peopled, are important contents of the workbook. However, we may not forget the impact of the professionals perceptions on ageing and on disability, as well as the perception of the social environment, the neighbourhood, all 'citizens' who are important stakeholders in the new approach: ageing people are part of the same society, have the same rights as all citizens in this unique society, and want to play a valorised role in this society. Many – by definition negative – perceptions of ageing people and of disabled people, and of ageing people with disabilities hinder a valorised contribution to society and don't contribute to the development of an open, warm, accepting society. The negative oriented philosophies (ableism and ageism) are part of this workbook in terms of active, healthy, agile ageing.

UNIT 1

THE AGEING PROCESS

1.1 Introduction

This first unit entails three different parts. The first part (1.2) focuses on ageing theories, perceptions on ageing, frailty and resilience. Ageing has many dimensions that have been explained through multiple theoretical perceptions. How someone ages is a very complex phenomenon related to bio-psychosocial factors. A good insight into their own believes, ageing theories and perceptions can guide educators in helping AAWID navigate the changes they experience and find ways to help them age successfully. The second part (1.3) addresses the current perspective and definition of intellectual disability. The aim of this chapter is to teach educators that disability refers to personal limitations that are of substantial disadvantage to the individual when attempting to function in society and thata disability should always be considered within the context of the individual's environmental and personal factors, and the need for individualized supports. That the IQ score is just one criteria of ID. The third and final part (1.4) is on AAWID and their changing support needs.

1.2 Ageing

1.2.1 Ageing in society

Start class with exercise 1 to find out how students are currently looking at aged people.

Class activity 1: Drawing of an aged person

- Give students 10 minutes to draw a picture of an 'aged' person.Giveno additional information on what to draw but ask them to include a title for the drawing, and to write down the sex and age of the person they draw.
- Then ask them to draw a picture of their own grandparent(s).
- Make the reflection: what do you think about ageing, what does this mean for the person, what does it mean for the care, what support does an older person need?
- Think about: maintaining autonomy and independence as one grows older.

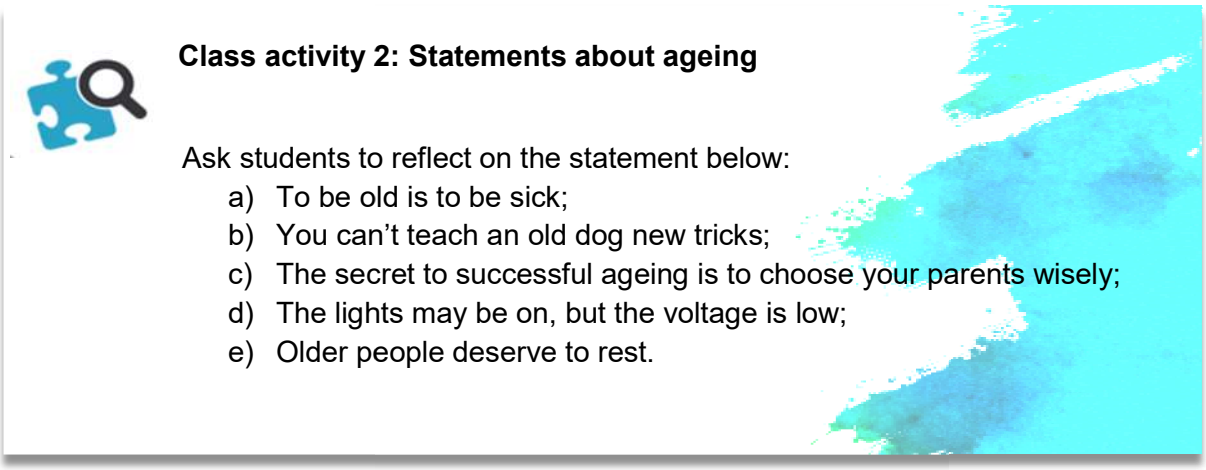
Additional information for trainer:

Most people first draw a stereotypical image of an elderly person: wrinkles, glasses, bent back, walking cane,.. . It is only when they draw a picture of their own aged grandparents that these stereotypes tend to disappear. In most studies it is found that negative attributes i.e. impairment, impotence, ugliness and isolation are the ones depicted in the students' drawings. Also older men were more negatively represented in comparison with older women – who were more often associated with positive attributes related to being a grandmother: kindness and interest in cooking.

Because of the improvement of health care we all become older. This has two consequences: there is a demographic shift in the general population wherefore there are more older people than young people, also called aging. A second consequence is the long life expectancy.

Ageing is part of life, an individual complex process for everyone. There are people of 70 years old who are vital, others of the same age have to deal with care needs. This is based on various determinants such as the environment in which the individual grew up, gender, culture, level of education and financial possibilities. Ageing is not a homogeneous or unidirectional process. [1]

Currently, chronic diseases play a dominant role, and in many cases they are incurable. This is especially important for old people, who often find a “bunch” of such chronic diseases. In old age, the presence of a particular disease is not even very important and significant, but rather the extent to which it limits the daily activities of the individual.



Class activity 2: Statements about ageing

Ask students to reflect on the statement below:

a) To be old is to be sick;
b) You can’t teach an old dog new tricks;
c) The secret to successful ageing is to choose your parents wisely;
d) The lights may be on, but the voltage is low;
e) Older people deserve to rest.

Additional info for the trainer:

a) To be old is to be sick. The reality however is: although chronic illnesses and disabilities do increase with age, the majority of older people are able to perform functions necessary for daily living and to manage independently until very advanced ages.'
b) You can't teach an old dog new tricks. Reality: older people are capable of learning new things, and continue to do so over the life course. This relates to cognitive vitality as well as the adoption of new behaviours.
c) The secret to successful ageing is to choose your parents wisely. Reality: genetic factors play a relatively small role in determining longevity and quality of life. Social and behavioural factors play a larger role in one's overall health status and functioning.
d) The lights may be on, but the voltage is low. Reality: while interest and engagement in sexual activities do decline with age, the majority of older people with partners and without major health problems are sexually active, although the nature and frequency of their activities may change over time.
e) Older people deserve to rest. Reality: The majority of older adults who do not work for pay are engaged in productive roles within their families or the community at large.

These beliefs are the basis for prejudicial attitudes, discriminatory practices and policies that perpetuate ageist beliefs. It can significantly undermine the quality of health and social care that elderly or disabled elderly benefit.

Need to add more on the different theories of Ageing? Ageing has many dimensions that have been explained through multiple theoretical perspectives. Support workers can use this knowledge as they plan and implement ways to promote healthy and successful ageing. More information about the different theories can be found here: http://samples.jbpub.com/9781284104479/Chapter_3.pdf

1.3 Ageism

Because of the perception in society (or context) elderly people experience daily prejudices. Once you get older, it's harder to be seen as a full-fledged person, just think of the labour market, access to quality health social services. This influences their health and well-being and has a negative impact on the individual ageing process [2–5].

Ageism can be defined as: “the stereotyping, prejudice, and discrimination against people on the basis of their age. It is a widespread and insidious practice, which has harmful effects on the health of older adults. Ageism is everywhere, yet it is the most socially “normalized” of any prejudice, and is not widely countered – like racism or sexism” [1].

Class activity 3: ageism

Trainer asks students to look online (smart phone, laptop,…):

“Look for hidden conventions and biased views in, for example, an advertising text, image, film clip, policy text, etc., and justify why you think this is ageism”.

1.4 Theories of ageing

There exist many different theories of ageing. In fact, the process of ageing has been described from biological and psychosocial perspectives. In this course we will only highlight the most popular theories. More in-depth information is available in articles 32 and 33 listed in the References of this Module 1.

1.4.1 Biological theories

Despite advances in molecular biology and genetics, the process of ageing remains a challenging endeavour for researchers. In fact, many biological theories tried to explain the mystery of aging, but neither of them appears to be fully satisfactory. There are the more traditional aging theories that maintain the idea that aging is not an adaptation or genetically programmed. More contemporary biological theories of aging talk about programmed and damage or error theories. The programmed theories stress that aging follows a biological timetable, more or less a continuation of the biological timetable that regulates childhood growth and development. “This regulation would depend on changes in gene expression that affect the systems responsible for maintenance, repair and defence responses” [33].

A damage and error theory that has been developed in 1882 by August Weismann is the wear and tear theory. This theory, which is still popular today, states that cells and tissues have vital parts that wear out resulting in aging. “Like components of an aging car, parts of the body eventually wear out from repeated use, killing them and then the body.

The damage or error theories emphasize environmental assaults to living organisms that induce cumulative damage at various levels as the cause of aging” [34].

1.4.2 Psychosocial theories

1.4.2.1 Activity theory

The activity theory suggests that society expects people to remain actively involved in their own community after retirement. Being active and socially involved is determinant for a satisfaction in life and longevity. Especially the quality of the activity is important. Activities that have a social component have a stronger impact on life’s satisfaction then solitaire activities[33].

1.4.2.2 Disengagement theory

The disengagement theory maintains that older people gradually withdraw from life in the community and from their social contacts. They are relieved from their responsibilities and have the time to reflect upon their life and end-of-life issues. Their responsibilities are handed over to the younger generation, keeping society in balance.

1.4.2.3 Life course theory

In the life course theory, aging and developmental change are perceived as continuous processes that are experienced throughout life. I.e., from the moment we are born, we all begin ageing. This ageing process occurs in several phases but differs from person to person depending on life events, the choices one makes, the policies and systems he/she grows old in. All of these experiences accumulate and determine how someone grows old.

1.5 Current perspectives on ageing

In 2020, we will try to approach the elderly in a more positive way. For example, we see them as independently active participants in society [4]. The environment must not be allowed to have a negative impact on this, but must have a facilitating effect in order to safeguard the right of every elderly person to a long and healthy life [6]. Below we discuss the current perspectives on ageing.

1.5.1 Healthy ageing

What is healthy living? “Health refers to physical, mental and social wellbeing” as expressed in the WHO definition of health. It involves raising the mortality age, the absence of chronic diseases, lowering the morbidity and good functional capabilities. A disease or disability may be present, but then it has a limited impact on their well-being. It is “the process of developing and maintaining the functional ability that enables wellbeing in older age” [6]. This is also called healthy ageing [7].

All this of course in a context in which older people can make their own choices in what they consider important [5]. This depends on their individualized intrinsic capabilities (such as their ability to walk, think, see, hear and remember) and the relevant environmental factors and the interaction between them. That’s the key to Healthy Ageing. Functional ability therefore means that it is important for older people to be able to meet their needs on the basis of their values and standards [5,8,9]:

- meet their basic needs;
- learn, grow and make decisions;
- be mobile;
- build and maintain relationships;
- contribute to society.

1.5.2 Active ageing

“Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age”. Active ageing aims to extend healthy life expectancy [4,9]. Active aging also allows people realize their potential physical, social and mental well-being throughout life and participate in society, providing them with adequate protection, safety, care, when they are in it need.” (UNECE Policy Note No.13 on aging issues June 2012). This definition is closely associated with well-being. However, the well-being of people is not only individual luxury: it has an important social dimension, for

example, in terms of increase participation in the labour market and reduce costs by health care.

Significant factors affecting health and well-being are social circumstances, as well as lifestyle. Lifestyle is considered as an area of priority attention, requiring the application of already accumulated knowledge and the entire volume of new information. The concept of "lifestyle" is a broad category that includes individual forms of behaviour, activity, and the realization of all opportunities in work, everyday life, and cultural customs that are characteristic of a particular socio-economic structure. The lifestyle also means the quantity and quality of human needs, human relationships, emotions and their subjective expression.

Active ageing means that the individual is not hindered by ageing. They continue to participate actively in society on a social, economic, cultural and spiritual level. This means that people can make flexible choices about how they want to spend their time, such as learning, working, free time and providing care. Despite illness or a disability, they remain an added value for their fellow human beings and are aware of their possibilities [4,7].

1.5.3 Successful ageing

There are various definitions of the concept successful ageing. Generally, it is recognized as an multidimensional concept. Scientists understand successful aging as the absence of chronic diseases and the ability to function effectively at the physiological and psychological level. First of all, "success" is associated with independence and overall satisfaction with life. If we want to age successfully, healthy ageing and active ageing play an important role. It implies that:

1. if there is disease, it has little influence on the individual in terms of limitations;
2. there is a cognitive and physical functionality and
3. the individual can actively make choices.

These 3 components of successful ageing are made up of the following 8 items.

1. length of life
2. biological health
3. mental health
4. cognitive efficiency
5. social competence
6. productivity
7. personal control and
8. life satisfaction

[7,10–13]

The degree of success of aging depends not only on physical health, but on the availability of flexible personal qualities. Among them - the ability to cope with stressful and conflict situations, self-efficacy and self-control. Important and calm attitude towards death. These qualities should be developed throughout life, not hoping that in old age you will suddenly understand everything and change.

1.6 An ageing person

It is not easy to give a single comprehensive definition of what an older person includes. In this workbook we look at an older person from a holistic perspective. A model for this is the bio-psychosocial model (BPS model). It describes human functioning as an interplay between biological, individual and social factors. Ageing cannot be explained solely by a personal, physical or mental problem. The level to which the person can participate in society and be active is also determined by the environmental factors in which the person lives.

Additional info: BPS model

From a biological point of view ageing is "the gradual irreversible changes in structure and function of an organism that occur as a result of the passage of time" [PubmedMesH]. This is a narrow definition, with an emphasis on biological changes such as:

- Central nervous system: IQ, personality, new skills, memory, recall
- Senses: slow in response, increase in falls, behaviour or personality changes, reduced socialization, dementia, depression, inappropriate social response [4]

Psychic ageing refers to human consciousness and the adaptability that ageing brings with it. As one gets older, the possibilities to adapt to new situations increase. Negative experiences are processed differently and people are less likely to be negatively influenced. With aging the perceptions are processed differently in the thinking process.

Social ageing refers to how the person experiences ageing and how society views the elderly. Poor social networks reduce the chances of survival in old age. [14,15]

One way of mapping human functioning on an individual basis is the use of the ICF, International Classification of Function, Disability, and Health, introduced by the WHO in 2001. This classification is based on the bio-psychosocial model and recognized as the third international standard to describe health and health-related states (next to mortality and morbidity). The ICF is widely distributed and is used in different countries and in different sectors.

Additional info:

In order to create a broader picture of an individual and not only to focus on the diseases, the ICF examines how they function in daily life and how they participate in different areas of life. The different hierarchically ordered concepts are about the affected body and organ systems, about the difficulties this causes in daily activities (such as physical mobility, cooking, household chores, transfers, personal care) and about the participation in the context, in society. [16–18]

According to the WHO (2010) are the aims of the ICF to:

- provide a scientific basis for understanding and studying health and health-related states, outcomes, determinants, and changes in health status and functioning;
- establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;
- permit comparison of data across countries, health care disciplines, services and time;
- provide a systematic coding scheme for health information systems.

In this workbook we will discuss the aging person from a holistic perspective. As a frame of reference we use the Quality of Life (QoL) model that gives the possibility to see and support the older person in all its aspects (see more in unit 2).

1.7 Ageing points of attention: focus on frailty and resilience

1.7.1 Frailty

Frailty is a term that is often used when talking about the elderly. However, the elderly themselves will rarely describe themselves as frail. For them, it is important to be viewed as someone who is ageing well. This view matches more with the current holistic view on ageing, both within research and in practice.

In line with the evolution towards a more holistic vision of aging, frailty has evolved from a purely physical concept to a concept with a more comprehensive interpretation. Frailty was originally conceptualized as something biological and multifactorial, involving human's dysregulation across many physiological systems. Based on this conceptual framework, two major definitions have emerged over the past decade: the frailty phenotype, also known as Fried's definition, and the frailty index [18,19]:

- *The frailty phenotype* defines frailty as a distinct clinical syndrome meeting three or more of five phenotypic criteria: weakness, slowness, low level of physical activity, self-reported exhaustion, and unintentional weight loss.
- *The frailty index* defines frailty as cumulative deficits identified in a comprehensive geriatric assessment.

Both definitions highlight the physical deterioration and functional limitations of ageing. Thus, frailty is referred to as having a greater risk of becoming seriously ill and dependent on others.

However, not everyone who is frail is also seriously disabled or in need of assistance. Frail older people can succeed in experiencing a positive quality of life. In other words, functional limitations is not an exclusive criterion for frailty [20].

A broader, more holistic view on frailty is shown in the work of Bergman et al. 2004 and Gobbens et al. (2010) [21,22]. Bergman et al. (2004) starts from the life course of an ageing person and outlines how frailty is influenced by biological, social and psychological factors[22]. Based on this conceptualization of frailty, Gobbens et al. (2010) developed an integrated coherent model of frailty. The model shows that frailty is a continuous process in which age and other life-course factors (e.g. education, income, gender, ethnicity and marital status, life style, life events, living environment) are referred to as important determinant. These determinants contribute to reduced physiological reserves and/or disease(s). Frailty

will than manifest itself in multiple areas (i.e. physical, psychological, social) and in multiple forms [20].

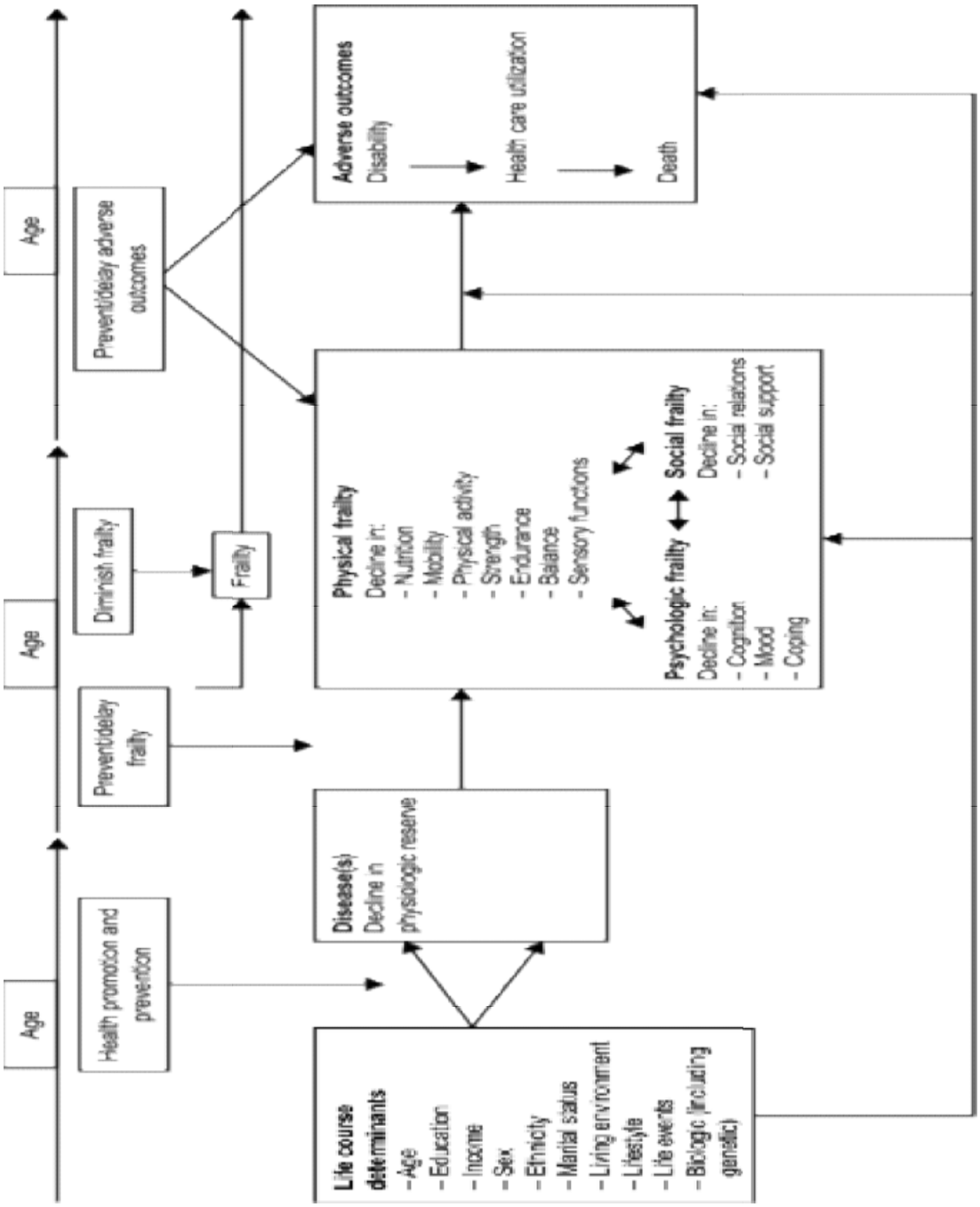


Figure 1-0-1: An integral conceptual model of frailty. Reproduced from Gobbens et al. (2010)

1.7.2 Resilience

A literature review highlights a number of important ideas of resilience.

1. First of all, resilience in old age is usually maintained, laying the foundation for continuity in performance. The older person can successfully cope with risks and setbacks in life. This is repeatedly confirmed by research in this area [23].
2. The second idea is coping, which aims at how older people adapt to the consequences of ageing and how they deal with the stress that these consequences can cause, e.g. in case of illness or loss [23].
3. The third important point is that dealing effectively with risks and adversity requires individual resources. Good health, maintaining activity, functioning, optimism, high self-esteem, flexibility, purposefulness, meaning, integration into the community, the preservation of a social role, social involvement and the social means offered by relational networks. Health, vital involvement, social participation and psychological well-being are also highlighted as dependent and independent variables related to resilience. [24,25]

Class activity 4: dreams of the future

Ageing takes place within the context of others – friends, work associates, neighbours and family members. This is why interdependence as well as intergenerational solidarity (two-way giving and receiving between individuals as well as older and younger generations) are important tenets of active ageing. Yesterday's child is today's adult and tomorrow's grandmother or grandfather.

The quality of life they will enjoy as grandparents depends on the risks and opportunities they experienced throughout the life course, as well as the manner in which succeeding generations provide mutual aid and support when needed.

Question for the students:
Can you tell how you see yourself at an age of 80 years? What do you need from your family, friends and community to age successfully?

1.8 Intellectual disability

1.8.1 ID in society

As mentioned above, society contributes to the extent to which a disability is considered to be a handicap. Everyone has a disability e.g. bad vision and needs a tool e.g. glasses for this. However, a definition could clarify which characteristics specifically take precedence over persons with intellectual disabilities.

1.8.1.1 Ableism

In society, the image of people is often still negative. We are going to call this Ableism. Ableism is the discrimination or prejudice against people with disabilities. Ableism can express itself through ideas and assumptions, stereotypes, attitudes and practices, ... It is often unconscious and people do not always realize the impact of their words or actions when dealing with people with disabilities. The perception of people with disabilities is strongly influenced by the media and the belief in science where disability is seen as a failure.

1.8.2 Perspective on ID

To clarify human functioning, we use the multidimensional model of human functioning according to the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD model contains criteria to identify limitations and possibilities. It can be used as a simple framework to provide targeted guidance. In the support we give to people, our own direction is central. We focus on the functioning of the person in daily situations, not on the limitations. The functioning is determined by the field of tension between the competencies of the person and the expectations of the person's environment. In the diagram of this model we see that the guidance has a central place. The aim of the support is to positively influence the functioning. The functioning of a person consists of 5 dimensions that are universal for every person with or without a disability. Knowing what the possibilities and limitations are in the 5 dimensions is important to provide the appropriate support.

The 5 dimensions:

[1] Intellectual ability is the general mental capacity. Intellectual ability is a certain level of development of the mental activity of a person, providing the opportunity to acquire new knowledge and effectively use it in the course of life, the ability to understand and comprehend. This is the basis of knowledge and behaviour of people (rationalism) in society. This includes reasoning, planning, problem solving, abstract thinking, understanding complex ideas, learning ability.

[2] Adaptive behaviour is the effectiveness and extent to which a person meets the requirements of personal independence and social responsibility, expected from his age and culture.

[3] Health is a state of complete physical, mental and social well-being and not just the absence of disease or other physical defects (def. WHO). Health has an objective and subjective component. This dimension is not isolated in itself but can be found in the other 4 dimensions.

[4] Participation, interaction and social roles. This dimension is related to the functioning of the individual in society. It refers to the roles and interactions in the field of living, working, education, leisure, spiritual and cultural activities.

[5] Context, meaning the environment and personal factors. By environmental factors are meant physical, social and attitude aspects of the environment. By personal factors we mean age, race, gender, social background, coping strategies, history and parenting style.

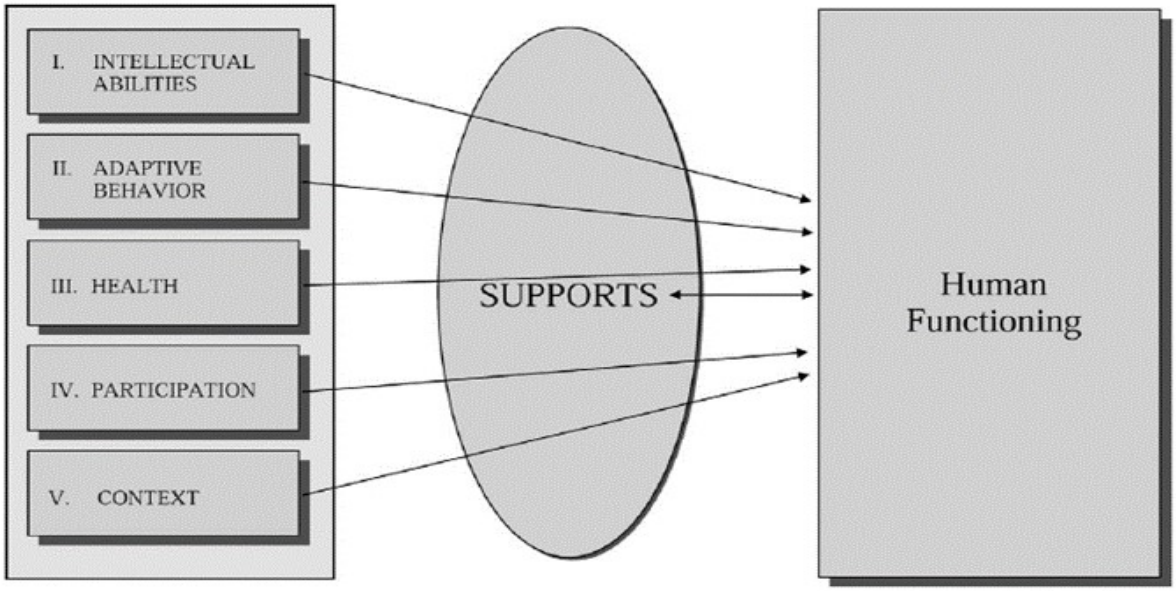


Figure 1-0-2: The multidimensional model of human functioning

1.8.3 The person with ID

As defined by the AAIDD, A person with a disability is someone who has limitations in his intellectual capacity and in his ability to adapt. These developmental delays occur before the age of 18.

- In the intellectual field this is reflected in problem solving, learning new things and reasoning. They may need, for example, guidance in learning to make difficult choices, make cause and effect arguments, orientate themselves in time and space. In our society we speak of a disability if the IQ is lower than 70 and 75.
- Intelligence (Engl. Intelligence; Lat. Intellectus - understanding, cognition) is defined quite varied, but in general, we mean individual characteristics that are related to the field of cognitive. By intelligence is meant the system of all cognitive (cognitive) abilities of an individual: sensation, perception, memory, representation, thinking, imagination, attention. The concept of intelligence as a general intellectual ability is used as a generalization of behavioural characteristics associated with the successful adaptation of a person to new life tasks. In the framework of the hierarchical approach to the consideration of intelligence, when characterizing cognitive changes in old age, “crystallized intelligence” and “mobile intelligence” are distinguished.
    - Crystallized intelligence is determined by the amount of knowledge acquired during life, the ability to solve problems based on the available information (give definitions of concepts, explain why stealing is not good).
    - Moving intelligence implies the ability to solve new problems for which there are no familiar ways. Assessment of general intelligence (Q-factor) consists of a set of estimates of crystallized and mobile intelligence.
- In people with intellectual disabilities, we often see adaptation problems in the social and practical skills. With good guidance and support, a person with a disability can often compensate well for this. A person with an intellectual disability often places more than another person in the centre and is concerned with what is going on in the here and now.This makes it difficult for them, for example, to empathize with another person and learned things become more difficult to generalise.

Further zooming in on adaptive behaviour, a subdivision into conceptual, social and practical skills is created. A few examples:

- “Conceptual skills: language and literacy; money, time, knowledge, memory and number concepts; and self-direction.

- Social skills: interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, empathy, rule-following ability and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills: activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone."

There are several possible reasons for the emergence of an intellectual disability.

Table 1-1: Overview of the possible reasons for the emergence of an intellectual disability

Genetic cause	Neurological cause	Other biological causes	Traumatic cause	Social cause
Down syndrome Fragile X syndrome	Brain malformation Problems at birth (ex. lack of oxygen…)	Maternal disease Infection during pregnancy Nutritional deficiency Because of an illness: Meningitis Whooping cough Measles	Head trauma during childhood	Environmental influences (alcohol, drugs, …) Exposure to toxins (lead, mercury, …) Labour- and delivery-related events

On the basis of this often found definition it is possible to identify a person with an intellectual disability. However, we are not satisfied with this description of persons with intellectual disabilities. A person with a disability cannot be described only by looking at his or her disability. Everyone has opportunities and can learn new things even if you have a disability. People all have their own ability to communicate, their way of moving and behaviour. As mentioned in the first chapter, the degree of disability depends on the context and how the environment deals with it.In addition, a person with or without a disability will function better, depending on his or her individual strengths and whether he or she is given sufficient personal guidance such as challenging learning environment, addressing problem-solving thinking, stimulating self-regulation.

Class activity 5: a case study

Jan is a 36 year old man with Down's syndrome. After the death of his parents Jan moved in with his sister's family. During the week Jan goes to work 5 days in a sheltered workshop. To go there Jan takes the bus (public transport). Because Jan sometimes feels alone and bored, Jan asks his supervisors and sister to volunteer at the residential care centre. He heard from his sweetheart that they are looking for someone there to help at the bar.

Questions for the students:

- What is your vision on people with disabilities?
- Do you believe in possibilities, in learnability?

1.9 Ageing and ID

1.9.1 AAWID in society

In the composition of the population we see that the group of elderly people with an intellectual disability is growing. This is due to better medical and social progress [2]. This presents us with a unique challenge to work together in the welfare and elderly sector and to explore new ways of thinking [12].

The symptoms of aging don't differ whether you have a disability or not, but the ageing process can be different [10]. This remains a point of attention for these elderly people as they often live in a more vulnerable environment, they often have no children or partner. The perception of elderly people with intellectual disabilities remains a social point of action.

People with intellectual disabilities often show signs of old age earlier than the average person. People with a mild intellectual disability and good support usually do not show a faster aging [2].

Four factors influence ageing [10]:

1. A first factor is the age-specific changes, namely those changes in older people with a higher incidence due to biological factors, an unhealthy lifestyle, an increasing vulnerability to the loss of independence. For example, less muscle mass, difficulty with sight and hearing, confusion, arthritis, ...
2. Another factor is the changes caused by ageing, such as the genetics of a person, the lifestyle and the environment.
3. Use of medication.
4. Developmental disabilities

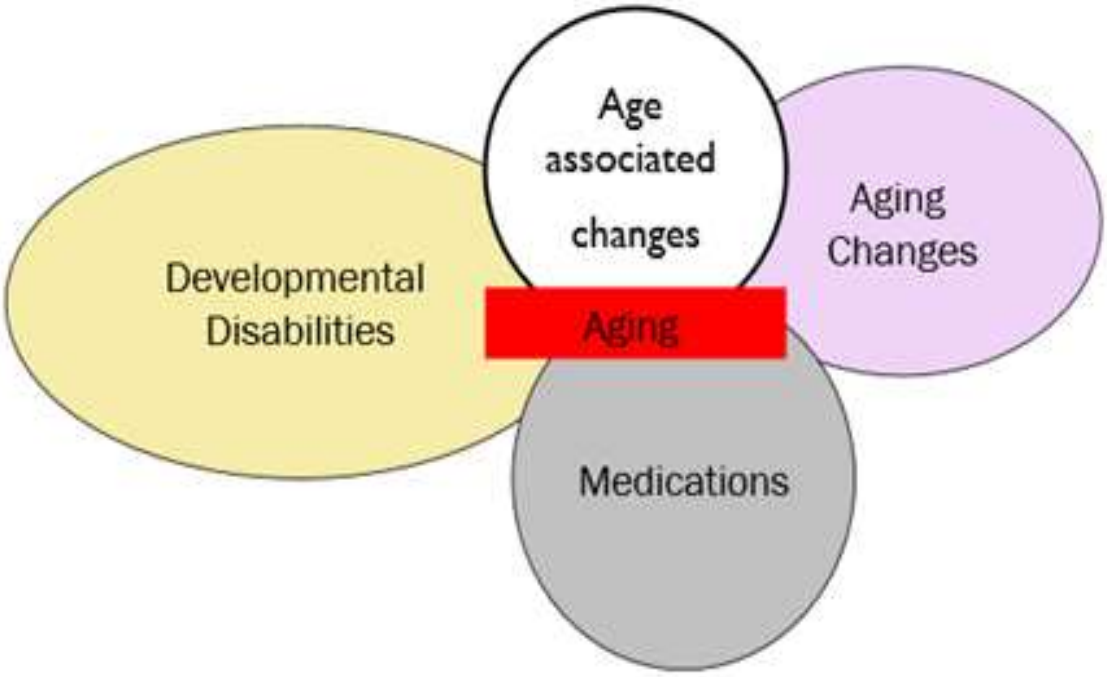


Figure 1-0-3: 4 influences that affect ageing [10]

When people with disabilities get older, they often have to face even greater prejudices than when they were young. We see here that they do not only have to deal with ableism, but also ageism. These reinforce each other, which makes it difficult to deal with them. In addition to prejudices, elderly people already have to deal with multiple life questions and changes in their roles. People retire, their siblings become grandparents, they become needy, people around them become ill or die,... As a result, they have different needs than in the past. As professionals who support the people with an intellectual disability, we need to pay attention to this and not shy away from these questions. It is important for support figures to address these issues and to look for support with these questions. In addition to the earlier life questions, we must be aware that elderly people with a disability will at some point become physically dependent, where a greater need for care by third parties will be desired. This means that the older person may have to move. In order to make this event as smooth as possible, it is a good idea to discuss this with the older person and/or his or her environment in good time.This allows these people to make their own choices in terms of ageing in place, if possible, instead of others making these choices for them.

1.9.2 Age of AAWID

As mentioned in the introduction, the life expectancy of people with intellectual disabilities has increased due to progress in social conditions, access to health and medical care. It is difficult to give the exact demographic figures for this group. Nevertheless, we notice that in people with severe intellectual disabilities and certain genetic disorders, such as Down's syndrome, the ageing process is initiated earlier. For example, because of vascular diseases. People with intellectual disabilities are more likely to have unhealthy lifestyles. These issues naturally mean that these people can expect a shorter life expectancy than the average person. [26]

In the case of people with intellectual disabilities, we must be aware that ailments in old age can sometimes be overlooked in medical diagnoses, as people are biologically older than their calendar age. In addition, we must be alert to the fact that people with disabilities can react differently to medication. [26]

People with intellectual disabilities are 4 times more likely to develop dementia than with the similar aged people of the general population. We see that the dementia process is faster for persons with genetic disorders (e.g. Down's Syndrome). [26]

In the case of people with a slight intellectual disability and good social support, we see little difference in ageing than in the average elderly person. The importance of good support and multidisciplinary guidance is great. We need to approach people with disabilities in a positive and flexible way, based on the possibilities and not the limitations.

1.9.3 Changing support needs

The ageing of people with intellectual disabilities means that they can sometimes suffer from several physical disorders at the same time (comorbidity). Often they have an unhealthy lifestyle. This calls for reflection on their changing support needs [12,27].

Most people with intellectual disabilities live with their families. As they and their parents grow older together, in later life they only live with one of the parents. Early care planning and adequate care for comorbid diseases, the timely learning of skills to adapt to the situation and autonomy are essential for the successful ageing of the person with intellectual disabilities. [12,26,27].

The disappearance of the family means that people with intellectual disabilities find themselves in an isolated situation at home, which can lead to loneliness. Their psychological needs require the ability to mourn all kinds of losses in their lives and express their emotions in doing so. [26]

An overview in Jenkins (2000) [26] shows the needs of bereaved people with disabilities:

- Acknowledgement of their grief needs;
- Access to counsellors and organizations who are sensitive;
- An accessible service;
- A service that both welcomes and values them;
- Counsellors who are creative in their approach;
- A professional, confidential service.

Needs vary according to the severity of the disability. For example, people with severe intellectual disabilities experience more unmet needs than people with mild or moderate intellectual disabilities [28]. People with mild intellectual disabilities want independence and social participation for themselves [29]. Research by McCausland (2010) shows that the common unmet needs of the population are education and financial skills, such as the ability to manage one's own finances independently. The needs concerning food and daily activities are met by persons with disabilities [28]. An elderly person with a disability needs supportive services, health surveillance and provision, family assistance [2].

For more in-depth information on how to promote healthy ageing in AAWID, read the summary report of the WHO (2001) that is freely accessible here: https://www.who.int/mental_health/media/en/20.pdf

1.9.4 A few points for attention

Older people with disabilities undergo more hospitalizations and transfers because of the health risks associated with old age. Compared to the general population, this is up to 5 to 6 times more common. However, thanks to these hospitalizations, it is easier to discover families in which a person with a disability lives [30–32].

In AAWID, due to comorbidity, the early recognition of health problems and the making of the correct diagnosis are not easy [2,10].

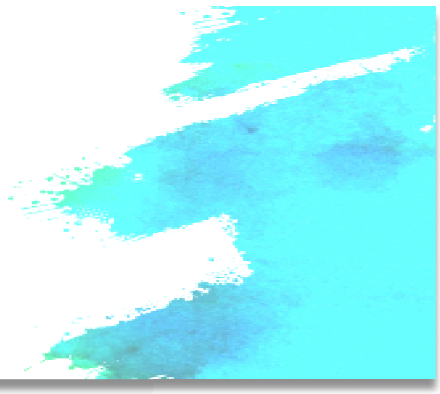
Older people with disabilities are a risk group to reduce their use of Healthcare services. Other factors that come into play are gender (male), being single, no disability certificate and no medical insurance [6].

Class activity 6: a case study

Take a look at the film shown on slide

Question for the students

Who do you see in the movie?



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UNIT 2

IMPACT OF AGEING ON QOL OF AAWID

2.1 Introduction

The purpose of this unit is to present a conceptual framework for support of AAWID. We aim to provide a limited outline of the concept of quality of life (QOL), its theoretical underpinnings and its application to the lives of AAWID. Although strongly intertwined, the support needs and -strategies/tools will be presented in unit 3.

The past few decades, public awareness and research into the Quality of Life (QOL) of people with a disability and ageing people has been growing. In both fields (e.g. disability and ageing), QOL is recognized as an important process indicator and outcome measure for assessing the effectiveness of treatment [1].

Defining QOL has proven to be a difficult task resulting in different definitions and conceptualizations. However, a detailed review of QOL models is beyond the scope of this chapter. Therefore the information gathered within this course will be limited to QOL models that are valid and reliable for AAWID. Examples of other QOL models and measurement frameworks can be found in the published work of [2], [3] and[4].

Despite the different QoL models and measurement frameworks, a cross-disciplinary review of the literature [5] shows a growing consensus on what can be considered as the core components of the QoL concept. In this chapter we will explain these core components through theory and practical exercises.

Furthermore, we believe it is important for professionals to understand the difference between QoL frameworks that focus on a narrow, or a broad conceptualization of QoL (i.e. Health related QoLvs. Holistic QoL). We also highlight the difference between quality of life and quality of care, and how QoL can be used as an outcome measure and a vehicle to implement quality improvement strategies.

The final purpose of this chapter is to demonstrate, through the use of international literature, how the process of ageing has an impact on the QoL of AAWID.

Class activity 1: Important object

Start this class with some exercises to acquaint the trainees with the concept of QoL:

(per 2 and group exercise) (10 minutes)

- Trainer asks students to bring an object to class. If not possible, ask them to take out their keys and choose one key.
- The trainers asks the following questions: “What does this object mean, reflect?”, “Why is this object important to you, in your life?”
- Student 1 tells his/her story to his/her neighbour (student 2), and vice versa. Afterwards, all student’s stories are told in the larger group. Student 1 tells the story of student 2 and vice versa.

Additional info:

→ This exercise helps students to reflect on what is important for themselves, that it is a personal/subjective story. It also helps to reflect on the importance of listening to what is important for others.

2.2 Defining the concept of QoL

*"A term that everyone understands, but which few can define" (*Campbell, 1977)

Since the second World War there has been a growing interest in the concept of "Quality of Life" (QoL), not only in the medical field, but also in other areas, such as sociology, psychology, economics, … recreation, advertisements. To show how popular the concept is, just enter the words "quality of life" in Google Scholar and you will find over 3 million hits, of which more than half have been published during the last 10 years. But although there are countless publications on QoL, there is limited evidence that indicates an overall understanding of what exactly defines QoL.

However, having a reliable definition, and a subsequent reliable measurement of QoL, is absolutely pivotal when outcomes of treatment have to be assessed [7].For example, professionals working with ageing people with ID sometimes have to make quality of life decisions based on their knowledge, experience and observations of the ageing persons. The professionals perspectives on expected QoL of AAWID is the crucial factor in deciding what is or is not important in the life of AAWID. Knowing that different interpretations and different definitions about QoL may lead to different decisions on what is important in a person's life, we strongly believe in the need for a valid and reliable definition and measurement of QoL. In this workbook, we therefore adhere to the quality of life framework as outlined by [7], a model that has been well described, researched and validated in the field of support for people with intellectual disability [8] [9] [10].

Class activity 2: WORD cloud

(individual exercise)(5 minutes)

Word Clouds are visual representations of words that give greater prominence to words that appear more frequently.

- The trainer facilitates the creation of a Word cloud by using a free online digital learning platform (example: mentimeter; Kahoot; …) .

The question that is asked to the students is:

- "**what is important in your life? Insert 1 or 2 words at a time".**

The trainer uses the output of WORD cloud to further acquaint students with the QOL concept.

- **"What do you see when you look at the result of the first question?"**

Additional info:

The Word cloud shows the students that QOL is related to more than just 1 domain/aspect of life.

2.2.1 Core principles of QOL

As described earlier, there exist many different conceptualizations of QoL and although discussions are still ongoing, there is an overall agreement that QoL adheres to a number of core principles. These core principles provide the framework for QoL measurement and application.

Class activity 3: WORD cloud Multidimensional (group exercise - 5 minutes)
→Start from the WORD cloud and ask students the following question:

- **Which of the words would you fit together? (i.e. What are the overarching categories/domains that reflect your answers?)**

Write the answers on the chalkboard or on a flipchart and refer to the definition by Schalock et al. (2002) (see below).

2.2.1.1 QoL is a multidimensional concept

The first principle states that QoL concept is multidimensional. As shown and visualized in the WORD clouds, QoL is more than being employed or having a home, it incorporates many different life domains. Within the disabilities field Schalock, et al. (2010) define QOL as:“a multidimensional phenomenon composed of core domains (see Table 1 p.) influenced by both personal characteristics and environmental factors” [11]. One’s QoL is the product of these factors and can be affected positively through public policy, quality enhancement strategies, quality thinking and outcome evaluation.

Note however that QOL is sometimes perceived as Health Related QOL (HRQOL) while the QoL construct that is used in this workbook starts from a holistic perspective. In the case of HRQOL, the focus is on how a specific disease or illness effects the daily functioning of an individual, especially the physical and mental health of the individual. The emphasis here is on pathology and deficits.

With regard to the holistic perception of QOL, health is an essential subdomain of QOL but does not cover the entire QOL concept, starting from a more positive connotation, and emphasizing the overall wellbeing and satisfaction of the individual.

Refer to the WORD Cloud. Some students might have entered a word that is related to health issues, but it is less prominent than other aspects of life.

While both QoL and HRQoL are mentioned in the literature, the ageing field uses more frequently HRQOL compared to the disabilities field. Yet, studies that focus specifically on the QoL of AAWID are either related to health related (HRQOL) or talk about how the current living situation (i.e. community living, supported housing, living independently,…) impacts QOL.

Class Activity 4: HRQOL (group - 5 minutes)

Ask students to reflect on what might be the reasons for these different perspectives,

starting from their own experiences in working with elderly, people with ID, or AAWID.

According to Bergland and Narum (2007) there are three different perspectives on QOL:

1. *The economic perspective* that perceives economic indicators such as 'income', 'living conditions, etc. as essential for a satisfactory life;
2. *The medical perspective* that regards QOL as Health Related QoL;
3. *The social sciences perspective* within which QOL is perceived as a more comprehensive construct incorporating more variables than just health and money [12].

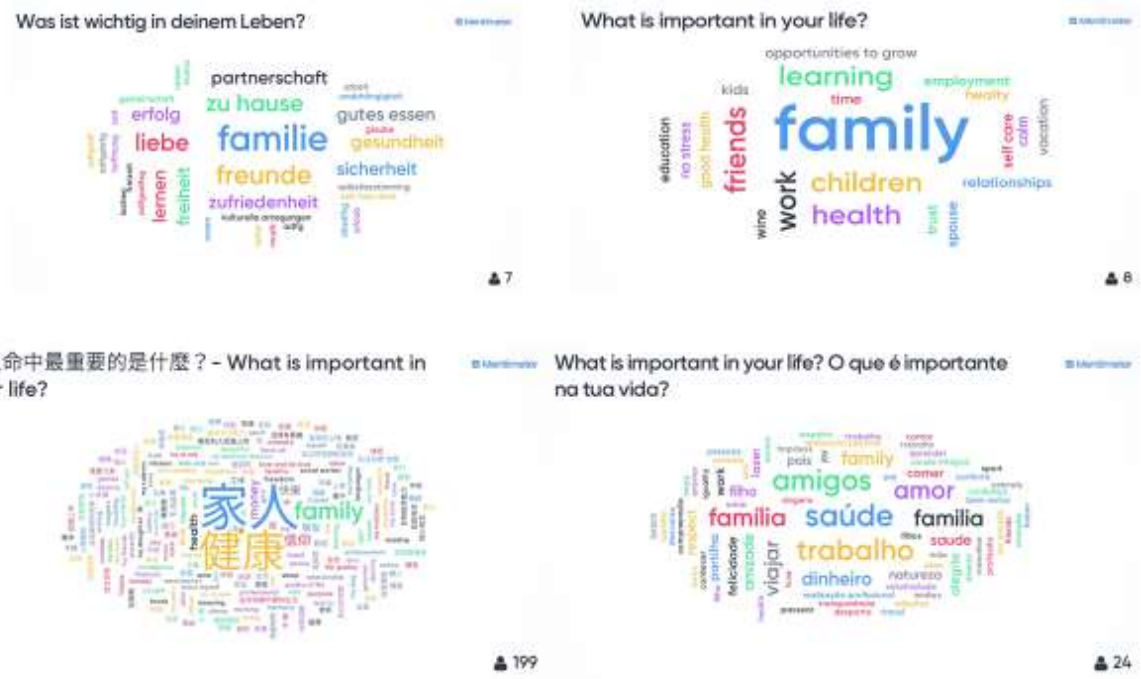
The field of disability has its roots in a medical approach but since the 1980s is gradually adopting a more social approach that is humanistic by nature and reflects the social justice, individual rights and equity origins of the current disability research [13]. For instance, most European policies and services for people with a disability focus on domains such as emotional well-being, interpersonal relationships, self-determination and on supporting people towards more independence and a life in the community. However, when individuals with or without a disability age, the perception of 'what might be important in life' changes and the orientation of the services shift from supporting independence to reproducing dependence and to a further disengagement from society [14]. A decline in health and cognitive abilities, inactivity, increased dependency and social isolation is often the explanation of why services shift their focus from 'taking care for' to 'taking care of' the ageing person ID.

2.2.1.2 QoL is universal- and cultural bound

As defined by Schalock et al. (2002), the QoL core domains are the same for all people, although they may vary individually in relative value and importance [1].

Class activity 5: WORD cloud universal (group - 1 minutes)

The trainer than shows other WORD clouds from Portugal, Tai Wan, The Netherlands, England,… (seeppt), and asks the same question: "what do you see when you look at these different WORD clouds?"



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2.2.1.3 QOL is subjective

Class activity 6:subjective(group – 5 minutes)

Ask students to reflect on the next statement:

- *"Having a good partner is important for a good quality of life".*
- "What and who defines what is a good partner?"

Ask the students to think about one of their ageing clients that is in their care and ask them to make a profileof what they think is important for this client. When they are finished, ask them to make another profile, and ask them to:

- write down what the client him- or herself thinks is important.
- Who determines QoL in the care and support of AAWID? The professional? The client?

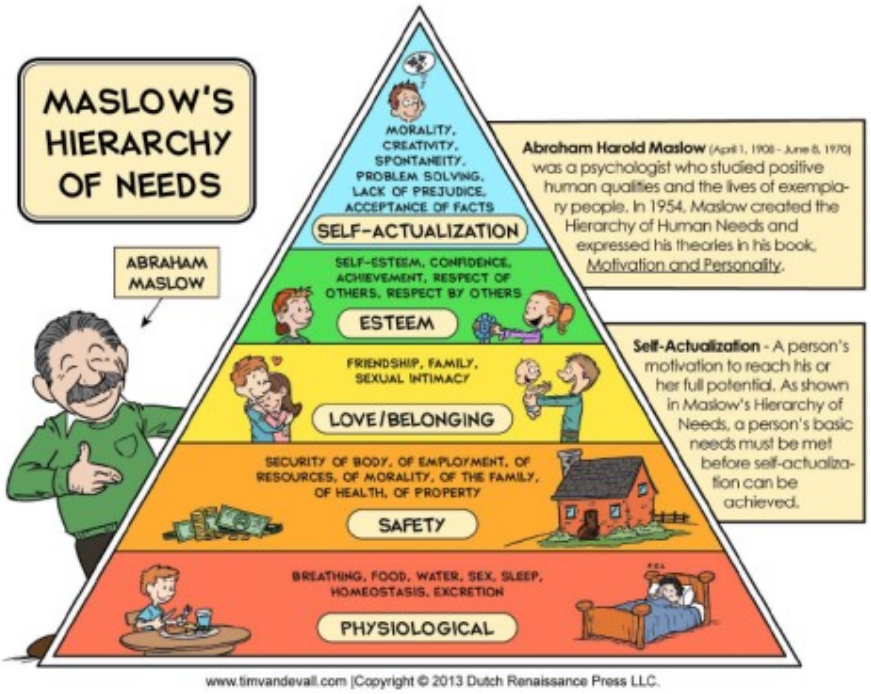
QOL has both subjective and objective components but it is first and foremost a subjective concept. Individual perceptions and values [1] (the subjective views ofa person) are known as a key component of quality of life, pointing out that a person is always the most suitable judge of his/her own QoL[15]. This doesn't mean that objective measures (e.g., having a job) are not important, but the relationship between such measures and personal sense of well-being is modest. For instance, having a good job doesn't mean you are having a good quality of life.

A QOL definition that emphasizes this component of QoL is the one formulated by the World Health Organization group (1998). The WHO defines QOL as: "An *individual's perception* of their position in life, in the context of the *culture and value systems* in which they live, and in relation to their *goals, expectations, standards, and concerns*." QoL is perceived as a broad ranging concept that is affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. QoL is strongly impacted by the goals, expectations and abilities to fulfil those expectations and goals [15].

When asking service providers or caregivers about their main goal of care and support, the most common answer is “a good quality of life for our clients”. However, what is often miscomprehended is that quality of life is not the same as quality of care[17]. Although a good quality of care and support is undisputable for service delivery, it does not necessarily guarantee a personal life of good quality for the consumers. Quality of care-systems outcomes strive for more efficiency, cost-effectiveness and consumer satisfaction and thus are not invested in creating valid personal outcomes related to personal well-being and a higher quality of life. Furthermore, in organizations that adhere to a quality of care approach, the staffs perspectives are usually more influential than the perspectives of the consumers [17]. So, If the outcome of service delivery for AAWID is to achieve a better quality of life, the main task of service providers is to listen and acquire knowledge on the individual’s perspective on life [18] his/her personal values, attitudes, aspirations and experiences. Thus, it is the AAWID that owns the process of care and support. The caregiver no longer ‘takes care of’ the AAWID, he/she cooperates and gives support to the AAWID, support that starts form a dialogue with AAWID.

Also, this support has to go beyond AAWID’s basic needs. Like Abraham Maslow’s hierarchy of needs pyramid (see figure 1), all citizens will reach a good QoL and be a truly happy when all needs, from the most concrete to the most abstract, are fulfilled. In the care and support for AAWID, the focus of caregivers is generally on fulfilling the basic needs of the clients, e.g. physiological and safety needs. According to Malsow, this is needed in order to achieve the more advanced and abstract needs (i.e. self-esteem and self-actualization) [19]. However, it should be clear that when applying the QoL framework in service delivery for AAWID, caregivers look beyond the basic needs of their clients. They use their ingenuity and (often very limited) resources to develop supports strategies for AAWID in order to help fulfil AAWID’s need for

- belonging and love
- respect or to be acknowledged
- knowledge and understanding,
- creativity and aesthetics,
- the realization of their personal meaning of life,
- becoming an integrated and valuable part of the world.



2.2.1.4 QoL is dynamic

QOL is not a static entity that remains unchanged during the course of life but is rather a **dynamic concept** that transforms with age (see graphic below), influenced by a person's dreams, expectations and aspirations [20]. It also implies that with the right support, a person's QOL can be improved. There is in fact an overall agreement that QoL is influenced by personal and environmental factors and their interactions. Studies have shown that QoL can be enhanced by self-determination, resources, purpose in life, and a sense of belonging (Cummins, 2005)

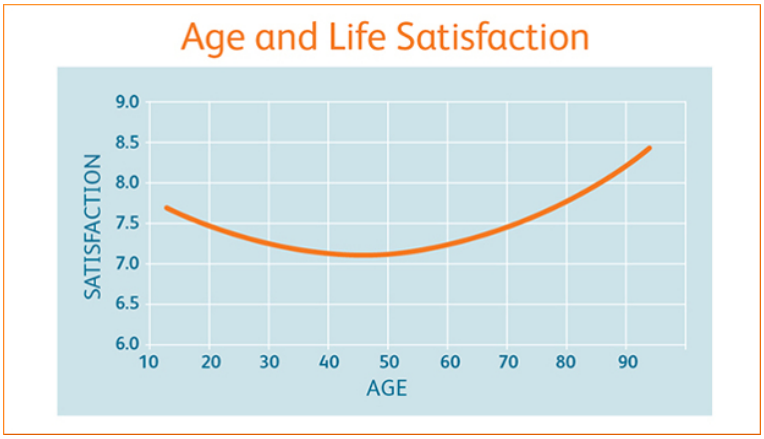


Figure 2-1: Age and Life Satisfaction. Kaiser Permanente Washington Health Research Institute

Most studies all over the world very often reveal a U-shaped relationship between subjective well-being and age. As shown in figure 1, younger people have generally a lower sense of well-being than people age 60 and older. In most studies happiness is high for 18- to 21-year-olds and then drops steadily until about age 40. But past middle age, the pattern began to reverse—gradually climbing back up to its highest point at age 98!

Contradict research that shows increased depression among older people as they experience illness, death of loved ones, and other losses common for the elderly. But aging also brings a greater acceptance of ourselves and our lives no matter how difficult circumstances may be at times. It's not that conditions necessarily get better as we age. It's that we have the chance to let go of our expectations and be more realistic about life's ups and downs.

2.3 QoL within the disabilities field

A QoL model that has been well described, researched and validated in the field of support for people with intellectual disa10bility [8] [9] [10] is referred to as the QoL model by Schalock and Verdugo.

2.3.1 Conceptual QoL model by Schalock and Verdugo

The conceptual model is composed of three factors, eight core domains and their respective indicators.

Table 2-1: Quality of Life Conceptual Framework

QoL Factor	QoL Domain	QoL indicator
Independence	Personal development	Education status, perso competences
	Self-determination	Choices, personal cont decisions
Social participation	Interpersonal relations	Social network friendshi family relations
	Social inclusion	Community integration, so roles
	Rights	Human and legal
Well-being	Emotional well-being	Contentment, lack of stress
	Physical well-being	Health and nutritional status
	Material well-being	Financial status, employme possessions

QoL factors can be translated as constructs that are from a higher order than QoL domains, they each comprised several QoL domains. “QoL domains are the set of factors that constitute personal well-being and represent the range over which the QoL concept extends. QoL indicators are QoL related perceptions, behaviours, and conditions that give an indication of the person’s well-being and are used as the basis for QoL assessment“ [1].

- **Personal development** is related to the acquisition of abilities, developing good skills to interact with the different life contexts. It implies an explicit will to learn new abilities, have opportunities to practice the abilities a person has; the possibilities to access new knowledge and desired information.
- **Self-determination** is related to the possibilities of taking decisions, having options & choices, finding respect for the decision taken and having an environment responsive to the personal preferences, opinions and decisions.
- **Interpersonal relations** are all the meaningful relationships, all the people the client knows, esp. the important and meaningful ones for the individual.
- **Social inclusion** is about the participation of an individual in the community this individual lives in, the roles acquired and practiced, presence in the meaningful social activities, supports received by the community members and services.
- **Rights & empowerment** is what a culture defines as norms and laws; if these conditions are respected, having access to all the possibilities that are offered to the people, in the same culture, for persons of the same age and gender. Having rights respected.
- **Emotional well-being** is a domain related to positive emotions about themselves. Enjoying life environments that are not stressing, having activities in which a person can experience his/her strengths and receiving positive feedback during daily activities, expressing affection and trustworthiness to the people present in his/her life.
- **Physical Well-being** is about the health, the presence of a good fitness and all the actions of prevention.
- **Material Well-being** is related to what a person earns, the belongings of a person, the housing conditions, availability of money.

Class activity 7: QoL and AAWID (45 minutes)

Unit 2 template 1

Ask students to reflect on the 8 domains of QoL, based on your experience in the field (practice, volunteering, personal experiences, …):

- Define what are the most important outcomes (results of your intervention) as a professional in relation to your ageing clients with ID (objectively).
- Define what are the most important outcomes (results of your intervention) as a professional in relation to your ageing clients with ID, from the perspective of the client (subjectively).
- Define what are the most important outcomes (results of your intervention) as a professional in relation to your ageing clients with ID, from the perspective of the relatives.
- Classify your outcomes: in which QoL domains your intervention will produce the intended result? Complete the exercise highlighting the overlaps or the different perspectives in the QoL domains.

This exercise can be done in the classroom. However, it might also be an interesting exercise to let students investigate whether the subjective perspective of AAWID (2) and their relatives (3) match with their own interpretations.

Remark: to know the subjective perspective of AAWID and the perspective of the relatives, you have to talk with AAWID about their dreams, expectations on the 8 domains of QoL and talk with the relatives to know their interpretations.

2.4 QoL and AAWID

2.4.1 Introduction

When a person becomes of age, it is not surprising when he/she reports more personal care needs and a decrease in functional or cognitive abilities. In such situations, it is essential to properly address these newly emerging care needs. However, when meeting these health care needs it should not come at the expense of other important life domains. For example, studies have shown how physical, medical and health-related issues are at the main concern of staff supporting AAWID. They express the need for more training and greater knowledge on these particular issues so they can support their ageing client group more effectively [21]. In this context, knowing how to activate or include AAWID is often considered of less importance as care workers assume that it is all part of the natural ageing process that older people lead more sedentary lives, go out less than younger people, and have fewer friends [14]. However, to the extent that AAWID become more dependent, inactive and socially isolated, it is clear that this is not a result of choice but is one of the aspects of their lives that they would most want to change [21]. To counterbalance the tendency of service providers to 'take care of' the elderly, the QOL framework can act as a facilitator to keep promoting change in the different life domains. It also forces service providers to use the perspective, goals and desires of their clients as the starting point for developing personalized supports plan.

QoL is a universal concept but as specified by Schalock, might vary individually in relative value and importance. Many indicators of QoL of AAWID are comparable to those of ageing persons without lifelong ID, although AAWID may have different experiences of QoL due to their often very different life course trajectories [22] [23]. In contrast to ageing persons without lifelong ID, a lot of AAWID spend their entire life in residential disabilities services, relying on (often changing) professional caregivers for their daily care and support [24] while contact with family and/or friends is often limited to non-existing. Then there are AAWID who grow old with their parents, and when these parents die, are confronted with abrupt changes in life, often leading up to inappropriate placements and sudden loss of lifelong networks [25].

There is very limited research on the QoL of AAWID so the aim of this section is to give an overview of some conceptual and qualitative work that has been done within the different QoL domains for AAWID.

2.4.2 Personal development

Like all older individuals, AAWID want to experience an 'active and successful' old age. There are some AAWID who want to take things more slowly after retirement, but most of them still want be to engaged in interesting programmes and enjoyable activities.

Despite current policy imperatives to promote active ageing for AAWID, this particular group is seldomly described as capable of embracing opportunities for growth. In fact, they are characterized as 'inactive' because they never really had a paid job or normal life to retire to. Furthermore, services – in many occasions - don't have formal retirement policies or pre-retirement planning leaving AAWID with no real understanding of the concept of retirement. Many are not aware of the consequences of their retirement or of their alternatives. Especially the older cohort of AAWID who reside in residential care homes or with ageing parents tend to be most disadvantaged in terms of having the opportunity to participate in leisure activities and developing life management skills [26]. For this cohort, leisure time often means more 'empty hours' or 'passive activities' (such as watching television or listening to music) and viewer - or less variety of activities, all attributed to the fact that AAWID need more rest. As an example, the next case of Jos, a 65 year old male whose sister explains that a transition from specialized care for ID to regular elderly care might not be in the best interest of Jos'QoL:

"In the specialized care facility, there is continuously movement. And although residents are sometimes arguing and hitting each other… it is still better than when he would go into a home where everything is always calm. Always calm and always the same. I think Jos still wants something that stands out. But I know him, in time he will just submit to the situation, he will settle because he doesn't know any better. (…) But please, give him something to do! Let him maybe work with plants. Please, let him do something so that he realizes that he is still alive!"

Furthermore, the notion of retirement can be very upsetting for AAWID who experience it as an abrupt retirement from their current life. Besides their fear of not attending their work or day time activities at the day-centre, the thing they fear the most is losing their close network of friends made at the workplace or day centre.

Almost two decades ago, the WHO (2000) released a publication to promote active ageing in AAWID recommending the development of special services that could provide a range of outcomes which could promote active ageing for members of this group. With respect to the QoL domain 'personal development', those support outcomes where:

- practical, leisure or life enhancing skills (i.e. making choices between alternative activities and allowing person to access community opportunities for work or retirement);
- a varied rhythm of life (i.e. involving preferred activities);
- recognition that challenge and productivity must continue throughout old age [28]

Class Activity 8: Personal development (5 min)

Reflect on the following two statements:

- "Like all older individuals, AAWID should be entitled to choose focus of their late life experiences, be it work, leisure, or some combination of the both."
- "Also AAWID who lose all reality of time and space are capable and entitled to choose their late life experiences?"
- "As a caregiver, how can you enhance the person's feeling of competence?"

2.4.3 Self-determination

Self-determination is a key determinant for a high QoL, both within the general population and AAWID. Issues of control and decision-making are crucial for AAWID as they rely more on others which may limit their options regarding basic matters such as how to spend leisure time, what to do after retirement, where to live and with whom to socialize [28]. As shown in the conversation below - between a researcher and a person with ID who just turned 65 (age of retirement) - it seems rather challenging for service providers to let clients shape their own lives.

I: And was there a possibility to choose where you would like to live?
R: No, because I would have stayed here, in Z, but they didn't allow it.
I: So, Z is where you would have liked to stay?
R: Yes, it would be my first choice. But they decided & said "R, you have no choice, you will have to leave Z!
I: Ok, and if you would have been able to choose where you would like to move, where would it have been?
R: I would have chosen another place called X, but it wasn't allowed. (X = institution for people with ID).
I: Why would you have liked to go there?
R: I would be much closer to my sister.

Some say that AAWID may not be involved in decisions about their care and needs because they are assumed to be unable to contribute meaningfully to the decision-making process while others suggest that it is linked to their cognitive abilities to either make - or express personal choice.

People with developmental disabilities are individuals whose abilities and disabilities are subject to wide variation. Obviously, individuals with physical disabilities who have no cognitive limitations will rarely, if ever, need a substitute decision-maker.

Many individuals with autism or an intellectual disability have expressive and receptive language abilities to communicate many of their needs and desires and have sufficient comprehension and reasoning skills to understand their choices. Some individuals with autism or an intellectual disability might not have strong expressive language skills, but can still communicate their desires through a variety of means and understand their choices.

From a QoL perspective, the question remains to what extent care and support practices succeed in allowing AAWID to shape their own lives 'freely'? Do practices limit the freedom of choice of AAWID by withholding alternative choices because of a lack of financial - or staff

resources? Or do they listen and respond only to choices that fit within their own service provision?

Class activity 9:Self-determination (15 minutes)

Reflect on the following discussions about how support staff can realize autonomy in AAWID

- "The key idea is not to have the client in focus, but to respect and take into account the client's focus. Professionals need to have the client's view in focus. They need to work with the client, and the client participates in all decisions regarding his or her life. Professionals should therefore always work together with the client, family or anyone else that the client chooses."

- "Staff should only support clients at the time that needs need to be supported. All things that clients can do on their own don't need support. This increases autonomy for the client. People with disabilities should be seen as a contributors to society. They are a resource to others. The staff must also have a 'risk approach' that allows the client to try, to take risks and to sometimes fail. Not be overprotective so that they hinder client's development and growth."

Additional information:

Both discussions are also about the need to invest in finding a persons' support needs. Investigating what is possible for a person and what is not achievable without having to take over…finding the right balance in supporting AAWID. Substitute decision-making is often used as a protective measure, e.g. to sustain someone from making choices that are harmful to their health and well-being. If substitute decision-making chooses the informal support network of the individual rather than formal types of support such as powers of attorney or guardianship.

- "AAWID should be able to exercise control over decisions and actions about where and how they want to live."

For AAWID, the concept of 'ageing in place' is interpreted as 'the belief that they should be supported to age in their accustomed formal support setting - be it a house in the community, a group home or other setting - 'for as long as it is deemed possible'. Bigby (2004) on the other hand, refers to ageing in place as "allowing the elder to remain in the living situation of their choice for as long as they wish and are able to". However, studies often show that participation in choice-making is also limited in this areas, mostly because of practical and structural barriers.

- As a caregiver, what can you do to know the person's desire about his/her last phase of life?

2.4.4 Interpersonal relationships

Social networks, family and kinship are known to be important components underpinning the quality of life for both older people in general [29] and people with ID [30]. Especially connectedness to family and friends appears to have an important influence on the quality of life of older people. Recent studies however have confirmed that people with ID have smaller social networks and less engagement in interpersonal relationships than people without intellectual disability [31] [32]. Social connectedness of AAWID is closely linked to their living situations. Living in smaller settings and/or being located within the general community is more beneficial for building or maintaining social relationships compared to living in large institutions and congregated settings [33]. However, some authors argue that the proximity to family and friends may be more influential to the AAWID's QoL rather than residential setting [34]. For instance, separation from family, friends and well-known caregivers has a considerable negative impact on the well-being of AAWID when they need to move to another residential service, especially when these services are far away from home [35]. Also the severity of the ID determines the quality and quantity of personal relationships with studies showing a more negative outcome for individual's with more severe disabilities [36]. Furthermore, the size of AAWID's social network declines with level of ID, especially when staff relationships and friends within their house are excluded [37] [38]. Most of the social activities of AAWID are with well-known staff/support workers or friends that live in the same house. AAWID with behavioural support needs have very poor or non-existent social networks outside their own immediate family and paid support staff. As a matter of fact, staff are often identified as the primary social companion and the biggest source of confidants for older people with intellectual disability [32] [38].

The majority of studies on intimate relationships of people with ID report that for the vast majority intimate relationships are non-existing [38]. In a study by McCausland et al. (2014) 99% of AAWID were single [38].

Class activity 10: Interpersonal relations (10 min)

Reflect on the following two statements:

- "As caregivers, we will remain the only supporting social network for AAWID when family ties are weakened or broken"
- "To positively influence the QoL of AAWID, studies have shown the need for reciprocity within social relationships. Are such reciprocal relationships likely to occur with staff?"

Additional information:

The importance of family connections for the social and community participation of older adults with intellectual disability should be reflected in policy. Measures for the maintenance and, where needed, the re-establishment of family ties should be prioritized for this older age cohort in particular, whose family ties may have been broken or weakened through the individual histories of institutionalization amongst this generation. This must also translate to practice, and services should place family involvement at the centre of individualized support plans, facilitating as far as possible their inclusion in person-centred planning, according to individual wishes. In instances of transition from institutional care to the local community, this should also consider proximity to family as this was significantly associated with family contact.

While staff relationships can provide more support for people with intellectual disability in terms of confiding and company, and provide closer and more frequent relationships than others including with other people with intellectual disability, such relationships are less likely to be reciprocal than those with other people with intellectual disability. Give some examples of reciprocity, what can an ageing person mean for his environment and vice versa?

2.4.5 Social inclusion

Since early 1950's there exists a broad consensus that all people should enjoy the same civil and human rights, as represented in the International Human Rights Law (1948) [39] and the United Nations Convention on the Rights of People with Disabilities (2006) [40]. Countries that ratified the UN convention endorse the full inclusion and participation of their citizens, irrespective of their age and type or onset of their disability. Also the deinstitutionalization movement in Europe, which started already in the 1970's, was intended to augment the QoL of people with ID and including them into the mainstream society by relocating them from institutional care facilities to a residence in the community. Moving to the community improves the QoL [42], because moving from an institution to the community more often leads to higher levels of involvement in meaningful daily activities [41]. The vast majority of AAWID continue to engage in a broad range of social activities, mostly within their local communities. Nonetheless, be aware that despite national and international policies that enforce full citizenship and social inclusion for people with ID, AAWID continue to be more socially excluded, especially the group of people with severe or profound levels of ID and those living in institutional settings.

Class activity 11: Social inclusion (15 minutes)

Reflect on the following to statements in terms of QoL:

- Moving to a residence within the community doesn't necessarily ensure possibilities to engage in culturally typical living experiences, nor does it predict having access to social, leisure and recreational activities in their community."
- *To show that social inclusion of AAWID means more than just physical inclusion. On many occasions, studies show that by moving some people become more lonely if other needs are not met (being dependent on others for transport; not having any friends in the neighbourhood, being far away from family members)…*
- Does inclusion also mean inclusion in mainstream care (e.g. elderly homes)?
    - How realistic is this interpretation of inclusion?
- Does inclusion mean that people have more than one choice?
    - How realistic is this interpretation of inclusion?
    - What arguments are there for choosing mainstream care instead of disability care?

Additional information:

This exercise is to see to what extent students are able to realize that it is not up to them to make this choice…they always need to include the perspective of the client and his network, as well as think about the support needs of clients.
The transition toward an inclusive society is fostered or inhibited by our individual belief systems: e.g. many people believe that living inclusively is not the right choice for certain people. As a consequence, especially for disabled people, segregated living in institutions is often the only option made available, disregarding the residents' quality of life.
Mainstream services need to adapt by modifying their policies, structures, methodologies, etc. in order for them to
become accessible – physically and mentally – for all citizens. The organizational HR-policy needs to concern itself with the missing competences of their staff, as they have to support new clients with different, unprecedented support needs. A paradigm shift, from the medically-oriented model to a community-based, social-supporting model is a precondition. As a caregiver, what can you do to enhance social inclusion?

2.4.6. Rights

As stated by the Graz declaration on disability and ageing [43], ageing people with disabilities should be seen as "equal European citizens, enjoying the same civil and human rights. The construct of QoL and the human rights for people with disabilities (UNCRPD) provide a global and fertile framework for rethinking how ageing people with disabilities can be included in society and treated as full human beings. Firstly, the QOL construct reflects the dynamics of personally desired subjective and objective conditions of life. It captures the essential domains of an individual's life situation, including his/her human and legal rights. Secondly, the QOL construct can be the link between the general values reflected in social rights and the personal life of the individual. In that way it can be the vehicle through which individual-referenced equity, empowerment, life satisfaction, and equal opportunities can be understood and enhanced [47].

AAWID have the right to:

- have the 'correct' information
- have privacy, to have a place of their own
- have their own identity
- have qualitative support
- to have a place to be (ageing in place)
- repose

Class activity 12 Rights (5 minutes)

Reflect on the following questions:

- Do AAWID know their rights?
- How do you ensure the right to privacy and integrity for AAWID in your place of work? As a caregiver, what can you do to enhance the performance of rights?

2.4.7. Emotional well-being

Emotional wellbeing has historically been seen as integral to a good QOL. Noteworthy is that emotional well-being is not the same as satisfaction with life. People with and without ID tend to report high levels of life satisfaction in general, mainly because people tend to adapt their expectations to suit their circumstances. Emotional well-being is about psychological well-being, self-esteem and the absence of stress. It's about growing old free of pain and discomfort, and about being free of worries or concerns. Assessments of the QoL of adults with ID show relatively high levels of emotional-wellbeing. How AAWID experience the transition into old age is individual and may lead to personal growth, but may also be stressful and lead to decreased well-being, loss of networks and support [45]. Psychological changes that occur within this population, as well as within the general population, and that may lead to lower levels of emotional well-being are: diminished levels of energy and quality of sleep, more rigidity, difficulties to accept physical deteriorations, augmented anxiety and insecurities, feelings of loss and morning, loneliness, difficulties to process new information, dementia, fear of becoming more dependent on others for the daily care and mobility,… .

Feelings of stress and anxiety are much higher in AAWID when they are occupied about what will happen to them with respect to their accommodation, social relationships and activities.AAWID have a lot of worries about major life changes prior to their actual retirement [28]. They stress about whether or not they have to change their residence and when and how they are going to lose their loved ones.This elevated stress can also be due to the fact that services do not involve them in the retirement plans. AAWID have fear of inactivity and lack of support when they transition to the older life phase [46].

Class activity 13: Emotional well-being (5 minutes)

Reflect on the following statement:

- Informing AAWID about what will happens when they become older is necessary for their emotional well-being, only if the person is able to understand this information?

Additional information:

Studies show that AAWID experienced the transition into retirement as abrupt, and they expressed a need for time to adapt to the new situation. AAWID also experienced a gap between knowledge and the wish for knowledge about ageing and retirement. Bridging this gap might decrease the fear of the transition and strengthen the possibility of self-determination in the process. AAWID will have a more relaxed life with increased self-determination. As caregiver, what can you do to enhance the emotional wellbeing of an ageing person?

2.4.8. Physical well-being

The vast majority of the general population might endorse health as an important domain of quality of life. Being healthy allows people to engage in activities, being connected to others and still play a role in life. As shown in unit 1, AAWID appears to have a much higher prevalence of health risk factors compared to the general population [48]. AAWID are more likely to have multiple co-morbidities (including mental illnesses) and to have a lower life expectancy that increases as severity of ID decreases. However, similar to the general population are the causes of death, being cardiovascular disease, respiratory diseases and cancers. Frailty and deteriorating QoL are often due to restricted access to preventive health care as well as unhealthy lifestyles [47]. Many AAWID take high doses of different medications, eat unhealthy foods, live sedentary lives and are as a consequence overweight. Besides preventive surveillances of health risks, AAWID can improve their health by taking on healthier lifestyles, better nutrition, and more exercise [48].

Despite a high prevalence of chronic conditions and indications that people with ID are generally less satisfied with their overall health compared to the general population [49], AAWID sometimes report positive feelings about their health conditions [50]; those who have positive self-perceptions about their health, and who acknowledge that certain aspects of life change when they get older, express more positive feelings about their future. Some AAWID even indicate having a better health after retirement. For instance, prior to retirement some AAWID may feel that their level of functioning does not correspond to their ability to perform work tasks. Despite efforts of their workplace to provide tasks and work that fit their level of functioning and limitations, they can be still in pain or feel tired. Some may report decreased coping skills at the end of their working lives or have a decreased sense of coping. So, for them, retirement is more of a blessing than a punishment. After retirement, they may be able to relax more, feel more energetic and had time to enjoy ‘other kind’ of activities more.

Like in the general population, old age does not necessarily start at the age of 65 for AAWID but depends on a number of risk factors, such as lifestyle, severity of the impairment, and physical, social or psychological risk factors. It is important to be alert for a decrease in the level of functioning of ageing adults to facilitate healthy ageing and a good QoL as a retiree.

Class activity 14: Physical well-being (5 min)

Reflect on the following statements:

- For an ageing person, the best way to stay fit, is to have a daily walk.
- A caregiver must inform the client about how to have a healthy lifestyle.

2.4.9. Material well-being

The living accommodation of a person is an indicator of the wellbeing of the person. People with a disability have the right to choose the place where they become old.

Most ageing people wish to stay in their familiar environment as long as possible. This wish is the same for AAWID. For a lot of people with disabilities it isn't simple to define their place to be (home), due to several changes 'of the place to be' during their life. A lot of AAWID can't choose where to live, AAWID with severe support needs mostly live in residential care.

According to the concept of quality of life, it's important that AAWID feel at home at the place they live. Having personal stuff (e.g. familiar furniture, clothes, photos, books, television, etc.) and living in a cosy and familiar environment, are indicators for material wellbeing. Also the adjustment of the living environment to the needs of AAWID, is an important factor to realize 'ageing in place'. Employment is another indicator for material wellbeing. Work contributes to a positive image of AAWID, AAWID can still contribute to society despite they are ageing and work gives financial resources. Work conditions for AAWID must be adjusted to their needs, e.g. working part-time, adjusted worktime. Having enough financial resources and having a say in how to spend their money, also contribute to material wellbeing of AAWID.

Class activity 15: Material well-being

Reflect on the following statements:

- "After the age of 50, ageing people with intellectual disabilities can't work anymore."
- "A residential setting is the best place to live for AAWID."

As a caregiver, what can you do to contribute to the material wellbeing of an ageing person?

2.5. Existential/spiritual well-being

When adults are ageing, they reflect about what they have reached in their life, they make the life balance. Ageing is a process of acceptance and adaptation. They ask questions as: 'Who am I now I'm ageing? What gives meaning to my life? How can I still contribute to society....?

Challenges for ageing adults are: accept their process of ageing, have a positive image of ageing (focus on the possibilities) and have a relevant contribution in the process of active ageing. These challenges are the same for AAWID.

In contrast to the general population, there is a lack of knowledge and self-determination when it comes to the process of ageing and end-of-live-care of AAWID. Within this context, far more attention should be given to existential supports to make these topics more accessible at an earlier stage in live.

References unit 2

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UNIT 3

METHODOLOGY WORKING ON QOL WITH AAWID

3.1 Introduction

The aim of this unit is to learn and teach support workers/educators how to use the QoL framework in order to facilitate successful ageing in AAWID. A good QoL starts with asking a person how he/she wants to live his/her life before determining what needs to be done to achieve these life goals/desires. All of these aspects can be situated within what is called 'Individual Support planning' (ISP) or Person-Centred Planning (PCP). Therefore we will start by explaining the key components of ISP and PCP.

Note

We realize that developing a ISP or PCP is time consuming and falls beyond the work scope of some professions (e.g. caregivers). The development of an ISP or PCP is an endeavour that is mostly coordinated by a (independent) facilitator, i.e. someone who is not directly involved in the care and support of AAWID. However, the development of an ISP or PCP is mainly a joint venture between the ageing individual with ID + his/her family and/or other people that know the individual well + his/her support workers.

It is during the daily encounters with the individual with ID that support workers can contribute in optimizing the individualized support plan. Studies have shown that support workers/caregivers "constitute a major influencing factor in the success of ISP or PCP implementation as they play a vital role in shaping the lives of people with ID through the quality of support they provide" [1]. Positive changes in the QoL of individuals with ID are not directly linked to ISP or PCP but to the professional skills of their support workers who listen, give instrumental and emotional support and show commitment to following the individuals' plan [2].

This training unit will provide tools and methodologies that should enable educators/support workers to develop these skills and competences. This unit is largely based on the work of Broekaert, R. Claes, C. &Vandevelde, S. Samenaan de slag. Naarvolwaardigpartnerschap in het persoonsgerichteondersteuningsproces. [Working Together. Towards a full partnership in the process of person-centred planning] Gent: Academia Press; 2014

Phase II (Planning) till Phase V (evaluation) is only for educators withEQF Level 6-8.

3.2 Planning for the future

"When we use the term 'person-centred', we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society"

Helen Sanderson, 2000

3.2.1 Person-Centred Planning

PCP is a multi-component complex intervention. Helen Sanderson describes PCP as: " …a process of continual listening and learning, focused on what is important to someone now, and for the future, and acting upon this in alliance with their family and friends. It is not simply a collection of new techniques to replace individual program planning. It is based on a completely different way of seeing and working with people with disabilities which is fundamentally about sharing power and community inclusion." [3]

A definition of person-centred approaches concludes that they are: "…ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Person-centred approaches look to mainstream services and community resources for assistance and do not limit themselves to what is available within specialist services." [3]

Class activity 1: S**ystem-centred versus person-centred approach** (in class/ outside of class)

(Worksheet 1 = 2 minutes + 10 minutes reflections)

Ask students to link the quotes to the correct column. Reflect on these quotes in relation to your own daily practice with AAWID or to how your own services are organised. Let them think about a concrete situation.

Additional information

Person centred approaches	Traditional approaches
• Builds on strengths and high expectations that everyone can and should enjoy the 'good' life	• Commences from a deficit and needs basis and low expectations
• Focuses on individual's unique interests and preferences	• Focuses on individual from a disability professional viewpoint
• Offers beyond what is currently available and works towards the future	• Looks to what is currently available from a service
• Tailors supports to achieve the person's goals and future	• Fits the person into the service
• Focuses on organising individualised, natural and creative supports and reduces reliance on the service system	• Planning assumes the person will spend most of their time grouped with other people with disability

Make it more concrete by letting students think about their own daily practices in order for them to better understand the differences and help them to realize that PCP in contrast to SCP is based on a completely different way of seeing and working with AAWID which is fundamentally about sharing power and community inclusion.

There are many different PCP approaches, techniques and tools with different applications according to the context and purpose in which they have been developed, for instance to teach knowledge and skills to individuals about available retirement options or healthy ageing, or to help choose leisure activities or a suitable accommodation, to talk about end-of-life issues, etc. Nevertheless, all PCP's have some common features [3]:

1. The person is at the centre;
2. Family members and friends are partners in planning; it is an alliance with people that know the person with ID well and who are willing to support that person in achieving his/her vision of the future;
3. The plan reflects what is important to the person, his/her capacities and what support he/she requires;
4. The plan results in actions that are about life, not just services and reflect what is possible and not what is available;
5. The plan results in ongoing listening, learning and future action.

Examples of formalized PCP approaches that have free online access are:

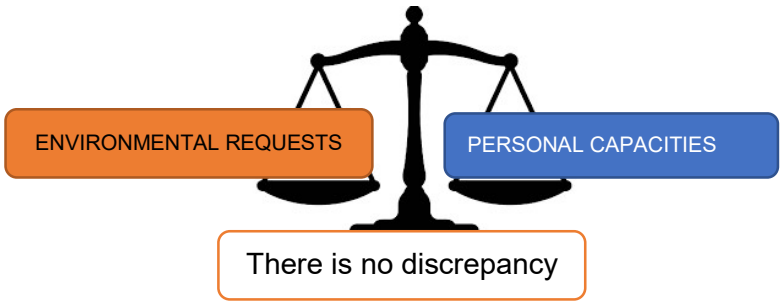
- Care and Support Planning: http://helensandersonassociates.co.uk/person-centred-practice/care-support-planning/
- MAPS or McGill Action Planning System: https://inclusive-solutions.com/training/map-making-an-action-plan-with-person-centred-processes/
- Essential Lifestyle Planning: http://allenshea.com/wp-content/uploads/2017/02/Essential-Lifestyle-Planning-for-Everyone.pdf
- PATH or Planning Alternative Tomorrows with Hope: https://www.imaginebetter.co.nz/what-we-offer/planning/path/
- It's my choice: http://mn.gov/mnddc//extra/publications/choice/Its_My_Choice.pdf
- Very interesting website with video's on frailty in AAWID: https://www.mapsresearch.ca/

Despite the popularity of using PCP to improve the QoL of people with ID, research remains rather limited demonstrating a moderate impact on social inclusion and self-determination.

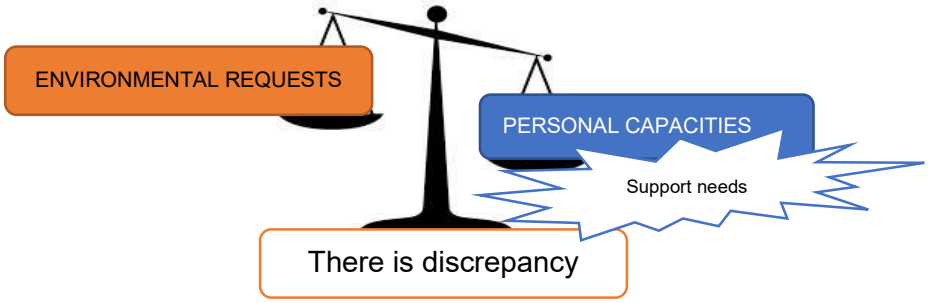
3.2.2 Framework: Individualized Support Planning

In order to optimize PCP for people with ID, Thompson et al. (2009) created a conceptual model called 'individual support planning' [4].

They define 'support' as resources and strategies that will bridge the gap between the challenges that a person experiences in life activities (i.e., person–environment mismatch) and the life experiences and opportunities (i.e., outcomes) that the individual values. For a person with a typical functioning, generally the requests from the environment correspond to the person's skills.



For people with ID, the demands of the environment are not aligned with the person's skills. However, that difference could be suitably compensated by providing adequate individualized support. And this is of course not different for AAWID.



For example, residential and ambulant services for persons with an ID have treatment- or support-plans, reports and client life stories that are written down somewhere. This is a rather peculiar choice knowing that many individuals with an ID don't know how to read (well) or write (well).The use of spoken or written language doesn't necessarily mean that a person with ID is unable to communicate. He/she just needs the appropriate support.

Going back to the theoretical framework of Thompson, he proposes a five-component approach (see Figure 1) to realize an individualized support plan.

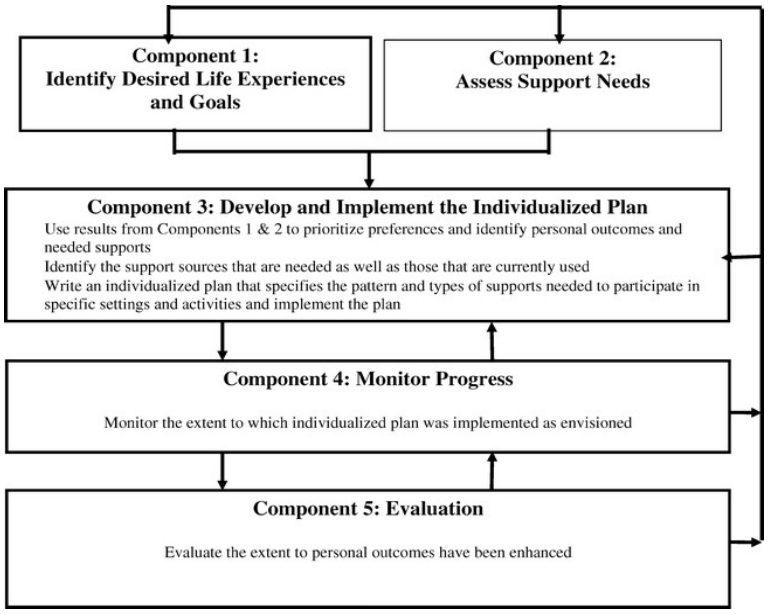


Figure 3-1: Conceptual model individual supports planning (Thompson et al. 2009).

For more in-depth information on the conceptual framework see Thompson et al. 2009, https://www.aaiddjournals.org/doi/full/10.1352/1934-9556-47.2.135.

This support plan always starts from the focus of the client, his/her dreams and wishes for the future on all 8 domains of QoL (component 1) and incorporates the type and intensity of support needs (component 2). Component 3 is about the development of an individualized plan that is based on components 1 & 2. This plan describes the activities of a person during a typical week and the type and intensity of the support he/she needs to do these activities. The implementation of the individualized support plan is continuously monitored by the team of support workers that evaluate the outcomes/goals of the plan (component 4). During the final phase, the desired outcomes of the person with ID - that have been influenced by the implementation of the support plan – are evaluated to see if things changed/got better. It is also a phase in which the team of supporters should check if the wishes and goals of the person with ID have changed over time.

This theoretical framework has later been translated into practice by Broekaert et al.[5]. It is this practical framework that will be used in the following sections to describe how educators can develop an individualized support plan for AAWID (see Figure 2).

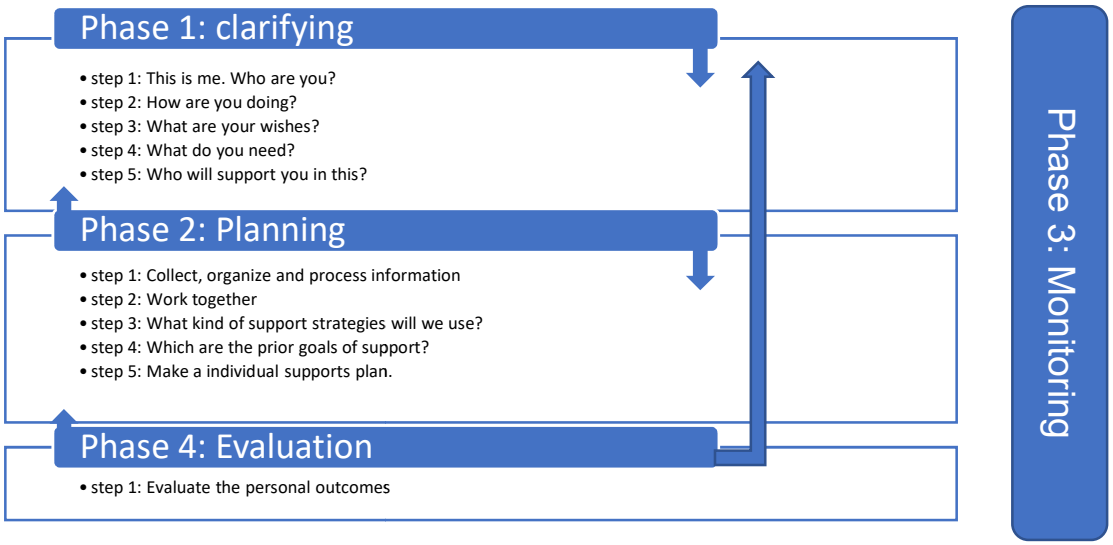


Figure 3-2: The person-centred support-plan [5]

Phase I

Note

Although changes have been recorded, in many European organisations for AAWID the support-plans are still drawn-up and consulted by professionals only. What's more, organisation-goals still have a major impact on the content of an ISP of the AAWID.

3.3 Individualized supports plan for AAWID

3.3.1 Phase I: Identifying and clarifying desired life experiences and goals

The first component of ISP is about exploring and identifying the **wishes** and the **support needs** of AAWID on **the different life domains**. Gaining insight into the **strengths** and **talents**, the **quality of life** and what to do in times of crisis.

People that should be present during this phase of ISP development are the AAWID + a facilitator

A facilitator is someone who

- *clarifies and identifies the desired life experiences and goals and the resulting support needs of AAWID on different life domains.*
- is person-centred and not system-centred
- clarifies the current life situation of the AAWID (strengths and limitations) as well as AAWID's wishes
- goes beyond thinking in terms possible budgetary, practical or medical limitations

3.3.1.1 STEP 1: Getting to know someone

The first step in developing an ISP is becoming more acquainted with the AAWID. The facilitator gets to know a person by first asking him/her about what is important to him/her. Obtaining insight into his/her dreams, talents, worries, life events, what to do if things aren't going so well, etc.

An example: " If you meet somebody new, what are the things that you really want them to know about you?"

Class activity 2: Get to know someone

(15 minutes, in classroom, individual)

Let students develop questions on how to get to know someone.

- "Create one question that will help you to get to know someone's hobbies"
- "Look for visualizations to help clarify your questions to someone who might not understand the spoken or written language well."

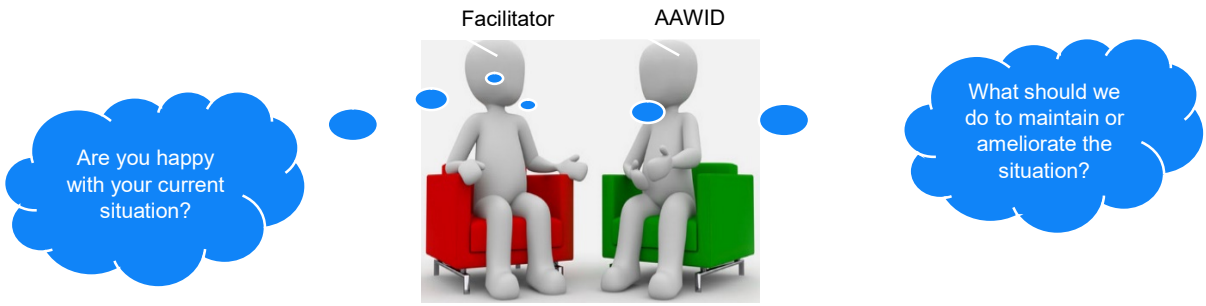
Communicating with AAWID

Getting to know a person and finding out what is important to him/her starts by communicating. One of the greatest barriers between AAWID and support workers is communication. As mentioned earlier, people with ID aren't always able to use the spoken or written language well. For instance, they sometimes have difficulties understanding certain words or sentences. They might fail to recall what has been said earlier. The stories that they tell are sometimes incoherent. They are also more likely, than members of the general population, to answer in ways they perceive are desired by the one asking the questions. This problem is often related to a sense of threat (e.g. perception of a power differential) or unease (e.g. being questioned in a noisy or unfamiliar environment). In other words, it might be quite daunting for support workers to get to know a person with ID, especially if the aim is to identify their choices and wishes.Accordingly, a support worker should always be aware that the communication skills of AAWID may vary and that accommodations may need to be made with respect to the spoken language and perhaps support communication techniques, such as using, augmentative and/or alternative communications.

Tips:

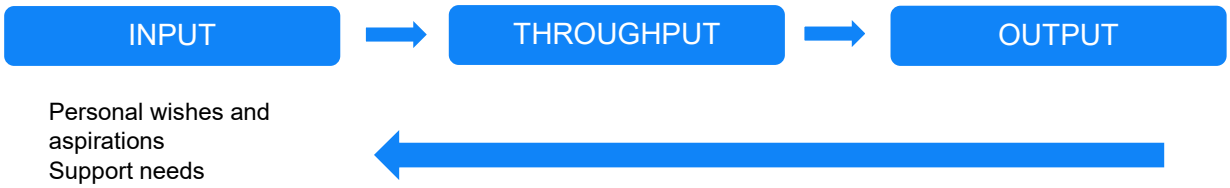
- ✓ **Observe** what the person is trying to communicate. Write down the context in which someone is trying to communicate, what you think it means and what you should be doing.
- ✓ **Questioning** family members, friends, support workers that know the person very well.
- ✓ **Posters** to help visualize the past, present and future with pictures and words.
- ✓ **Photovoice** is a technique that uses pictures/photos taken by the person (or by someone else if necessary) of things the person likes.
- ✓ **Visualisations**: sometimes it helps to use pictograms or symbols to clarify written or spoken language.
- ✓ **Technical supports** such as for example computer adjustments

3.3.1.2 STEP 2: What is the current QoL?



Different assessment tools exist to gather information about the QoL of people with ID. However, tools that focus on the QoL of ageing persons with ID are scares and not freely accessible. To gather information about the current QoL of AAWID we developed some questions based on existing QoL tools for ID combined with findings from international literature on the QoL and support needs of AAWID (see QOL AAWID annex). These questions should enable support workers to gather as much information as possible about

the current situation (outcomes) of a person's life. Note however that this is not a standardized questionnaire! The qualitative information can be used as input to change or develop the individualized support plan and to make an update of the support needs. Robert Schalock talks about 'right to left thinking', in which outcomes measures are used as input for a new cycle of individualized supports planning.



The questionnaire (see Annex) comprises the 8 QoL domains and an extra domain on existentialism/spirituality.

Guidelines for conversations on QOL when using the QOL AAWID questionnaire

1. Make sure the conversation takes place in a room that is comfortable and ensure privacy and confidentiality. The actual conversation about life domains should occur after you have spent a little time 'getting to know one another.' This pre-conversation time can be used to talk about topics (e.g. the person's hobbies, or family life) that are of interest to the person. Tell something about yourself as well. This will create an open atmosphere that leads to more confidentiality.
2. A family member, or another person that knows the AAWID well, can be present during the conversations to assist in clarifying certain issues. If this is the case, this person's input should focus on giving examples and helping clarify the question, NOT to answer for the AAWID. In addition, during the conversation, you should have a direct line of sight to the individual so that you can focus on the individual during the conversation.
3. Make sure you communicate clearly about the goal or purpose of the conversation and assure him/her that the conversation is not a test. In essence the clarification phase is to ameliorate the QoL of the person, taking into account his/her own priorities. However, it is better to explain everything from the begin, so also the process of planning and evaluating.

→In layman's terms, the conversation is about the life trajectory of AAWID, in which he/she explains his/her wishes for the future, about the meeting with a supports group during which concrete goals will be put forward in order to accomplish those wishes for the future, the permanent monitoring of these goals and the evaluation of the supports plan.

4. If an item is difficult or the respondent does not provide an answer, the best procedure is to go come back at it later and ask about the question again.
5. Do not hesitate to confirm the answers with additional probes, especially when you're not sure an accurate answer is given.
6. If the individual either finds the conversation stressful or asks to leave, then the best procedure is to give the individual a rest period or come back later.
7. Make every effort to keep your language clear and simple, and check often to see whether the person understands what you're saying. Be patient.

Tips

- ✓ *Use terms that AAWID understand. What to do if the person has different interpretations about certain concepts. For instance, the concept of money. A person can have a positive experience about his finances but in reality he is in debt. It is important to realize that there are no right or wrong answers when assessing the QoL of a person.*
- ✓ *If a person is unwilling to talk about a specific subject, even in the presence of a proxy, respect his/her wish to privacy.*
- ✓ *Take note of all important information and let the person see what you are writing down. If possible, and only with the approval of the person, record the conversation (tape recorder or video recorder).*

The following exercise can also be done individually at home, as a preparation for exercise 4

Class activity 3: AAWID QOL questionnaire (1 hour, in classroom)

Tools needed: AAWID QOL + Unit 3 – Focus 2

Make groups of 2 students. Give each group a number 1 or 2.

- All groups: "Make a checklist of things you need to do and things you need to say to a client before you start a conversation on the QoL domains"
- Group 1: "Using the QOL AAWID questionnaire, rewrite the questions or add other clarifying questions to match with the communication needs of your client for the following QoL domains 1. personal development, 2. self-determination, 3. interpersonal relationships, 4. social inclusion". The aim is to get in-depth information on the topics and to make sure the client understands the questions.
- Group 2: "Do the same exercise for the QoL domains 5. rights, 6. emotional-, 7. Physical-and 8. material well-being, 9. spirituality".

Class activity 4: Having a QOL conversation (3 hours, in classroom)

This is a role play exercise

Tools needed: each student should have 2 X QOL AAWID toolson paper + 10 x the observation templates (see annex 1)
Role play groups ofmax. 5 students + 1 AAWID (invite AAWID to class as co-trainers to do the role-play with the students – 1 AAWID per max. 5 students).

- Each student exercises with the AAWID QOL.
- Each student, except student 1, interviews the AAWID on two domains of QoL. Student one, explains the purpose of the exercise and the QOL questionnaire to the AAWID. He/she then starts with questions that tackle for instance the domain personal development. The other 4 students observe and take notes about what is good, what could be better, what is missing,… .
- After the role-playing, ask AAWID to give his/her reflections on the exercise. Did he enjoy doing the interview? What could have been better? Did he feel that the student was listing, giving enough time to answer,

After about 1 hour, all groups take a 15 min. brake.

- After the brake, the students do the interview with another AAWID, each tackling other QoL domains.

Additional information:

Invite AAWID for a few hours only (max. 3 hours). Give these co-trainers a present or money for their participation.

Activity at the workplace 1: QoL conversations at the workplace

- Give students the assignment to do the entire interview with one of their clients at the workplace. Let them bring their notes and remarks (difficulties they have encountered) to the next class.

Additional information:
If students are not in contact with an AAWID, they can do the interview with an elderly person without ID.

3.3.1.3 STEP 3: What are the hopes and dreams?

When gathering the information about the current QoL of AAWID, it is possible to also discover future hopes and dreams. The next step is to prioritize the dreams and work out a plan of support (see step 4).

When defining hopes and dreams for the future, know the difference between **'what is important to'** and **'what is important for'** AAWID. What is *'important to'* a person is about what the person is saying and/or showing. AAWID have often lived in settings where they didn't learn to speak for themselves but said what they were taught to say.As a support worker it is imperative to not just listen to what they are saying but also observe and reflect on that answer.

What is *'important for'* a person includes issues as what we think is important for that person, e.g. healthy ageing, safety, social skills, … . Both 'important to' and 'important for' can be in conflict. Finding the correct balance between the two is quintessential. For example: Theo, who 6 months ago had an accident with his bike and broke his hips, would love to ride his bike at least one's a day (important to him). His support worker thinks that riding a bike is no longer safe for him (important for him).

A support worker should always help AAWID to maximise the control they have over their lives.“This means that you are helping people find the balance between ‘important to’ and ‘important for’ that works for them” [6]. The best support plans reflect the balances between competing desires, needs, choice and safety.

Class activity 5: What is important to – what is important for a person

Use Unit 3 – template 2

Complete the following questions:

- “Think about a person you have recently cared for and reflect upon a situation in which you have done things because you thought it was important for him/her. Write your thoughts in the left column.”
- “Write in right column what you think is important to him/her”

Reflect on this situation with the following questions (maximum 1 page):

- Did your actions help the person maximizing self-control in this situation or not? Explain.
- Did your actions reflect a good balance between the clients’ desires, needs, choice and safety and your own ideas on what might be important for the client? Explainyouranswer.
- Would you do things differently and how?

Additional information

“Having people stop and think about the answers helps them determine whether they are taking both what is ‘important to’ and what is ‘important for’ into account and whether or not there are significant things that still need to be learned. People think they can do it as soon as they hear it, but they need practice and feedback” [6]

3.3.1.4 STEP 4: What kind of support is needed?

To identify the correct support activities or strategies, you ask yourself the following questions:

“what does this person need to successfully and satisfactorily pursue his/her wish/dream?”.

- Which are the skills or competencies, needed to fulfil the wish/dream?
  - For which of these skills/competencies does the AAWID need support?
  - What is the nature of the support?
    - ✓Type of support: monitoring, verbal/gestural instructions, partial physical assistance, complete physical assistance
  - How often is this support needed?
    - ✓Frequency: maximum once a month, once a week, few times a week, every day, hourly, continuously
- What are financial, structural and social needs?

Note

The Support Intensity Scale Adults (SIS-A) is an assessment tool used to measure the pattern and intensity of supports that a person with ID requires to be successful in community settings. More information about this tool is available on the website of the American Association on Intellectual and Developmental Disabilities (AAIDD): https://www.aaidd.org/sis/product-information[7]. The AAIDD website also grants you free access to the SIS White Papers (https://www.aaidd.org/sis/white-papers).

The assessment is done through an interview with the individual and those who have known the individual for at least three months. The interviewer is recommended to attend a professional development/training workshop on how to score and administer the SIS-A. As an example, see the case-study of Jacob which is based on a completed SIS interview form: http://aaidd.org/docs/default-source/sis-docs/jacob_ryan_case.pdf?sfvrsn=b19e3621_0. The instrument has been translated in many languages but has copyright restrictions.

Although the SIS is specifically developed for adults with ID, it has not yet been validated for AAWID. A Tool that is currently being validated for AAWID, but which is still under construction, is the Questionnaire on Quality of Support (QoS-EPID) by HadewychSchepens (Flanders, Belgium). This instrument will be used as a reflection tool for both the client and his/her proxy and organisations.

In Spain, the university of Oviedo developed “the Interview for Needs Evaluation of Ageing People with Disabilities (ENDE)[8]. This instrument is freely distributed athttps://www.dropbox.com/s/vdpwoqvbg3pmyxo/Entrevista%20ENDE_Alcedo%20et%20al..pdf?dl=0.

Although most of the support needs mentioned in the Support Intensity Scale (SIS-A) are similar for the ageing population, there are some additional needs that may arise during the ageing process of AAWID ([8]. The table below gives an overview of these additional support needs aligned with some practical tips or support strategies. This table is developed using literature on the topic [8][9].

Table 3-1: Additional needs that may arise during the ageing process of AAWID, aligned with practical tips or support strategies

Domain of Quality of Life	Indicators	Support needs	Support activities/strategies
Personal development	Education	- Maintain and elaborate skills; learn new things, have new experiences even after retirement. - Gaining knowledge about the process of ageing and retirement - retirement planning: Learn how to maintain or reduce current work or day-time activities.	- Promoting an active (inclusive) lifestyle. - Provide age and ability appropriate (daytime and leisure) activities that are meaningful and desired by the person - Getting to know or maintaining the lifelong passions of the person - Organize workshops on ageing, retirement, end-of-life issues - Give the possibility to retire gradually; Enabling a varied rhythm of life (i.e. involving preferred activities). - Mentor older adults volunteering to mentor AAWID in leisure retirement activities
	Feeling of competence Acquirements/achievements	- Opportunities to do activities that are important to the person; to be able to achieve valuable goals	- Adjusting type of job/activities or task demands to the support needs of the person. (e.g. add cognitive and assistive technology, more support in transportation, …) - Recognizing that challenge and productivity must continue throughout old age;
Self-determination	To have control over their life/autonomy	- Making decisions about the future on all life domains	- Provide training for AAWID in making choices, goal setting in various life domains, planning for the future.
	Choices, personal goals	- Making daily choices: which clothes to wear, which food to eat, when to eat, when to rest or sleep, … . - Making choices about their own health care. - Making choices about living arrangements; the opportunity to 'age in place' or to move to another setting (independent living, community home, elderly home, …).	- Allow for flexibility, follow the rhythm of the client - Promoting decision making aides (e.g. graphic and colour-coded information) - Fostering independence - Getting to know where the person wants to life when getting older; explore possibilities with the client and his network; use of peer-support An example of supported decision-making, see the video by Watson & Joseph (2011). https://vimeo.com/29367328 Supported decision making quick reference guide: https://providers.dhhs.vic.gov.au/sit

Domain of Quality of Life	Indicators	Support needs	Support activities/strategies
			es/default/files/2017-07/Supporting-decision-making-quick-reference-guide.pdf article: byShogren et al. (2017)
Interpersonal relationships	Interactions	- building a social network	- Creating opportunities to get to know other people - Take actions to maintain and elaborate the network of the person (promote a network approach). - Take actions to recruit, match and support volunteers
	Relationships	- keeping in good contact with family and friends - To have reciprocal, respectful and unpaid relationships with family and friends.	- Strategies enabling and maintaining close relationships; Take actions to maintain former relationships/connections of the past (e.g. encourage family and friends to install buddy systems, and to regularly pass by at the home) - Support informal caregivers, empower members of the network - Support AAWID when they lose friends, family members (members of their natural network). - Listen to the life story of AAWID by using pictures of family, friends, familiar places…(e.g. what does this person mean for you?) - Have attention for the physical and sexual needs of the person.
Social inclusion	Participation	- Participation in preferred community activities. e.g. being member of a club - Participation to mainstream services.	.- Enabling community participation by providing aids, equipment and adaptations for physical changes, mobility devices and cognitive devices. - Provision or enabling meaningful social interactions. - Staff, families, volunteers doing things together: watching TV, having coffee, playing games, … - With a community builder supporting activities and developing networks. - Staff organizing inclusive support by volunteers
	Roles	- Contribution to society, social engagement	- Create opportunities for AAWID to have a role in society, e.g. be an employee, be a volunteer. - Promote the recognition of the social role of people with disabilities, that is the ability to express an active position and participate in the

Domain of Quality of Life	Indicators	Support needs	Support activities/strategies
			context they live in, taking responsibility (small or large, durable or temporary).
Rights	Human andcivilrights	- Have an own place, a place to be. - Have their own key of their room, house - Right to repose	- advocate and take action for the human rights of AAWID
Emotional well-being	Contentment	- Have a dignified last phase of life - Good mental health	- Adapting the home or residence in an effective way (e.g. for dementia) - Making AAWID feel at home and consulting on the matter with family, previous support workers, … - Capturing grief responses, rituals, attending to funeral
	Lack of stress	Following their own rhyme Familiar environment	- Reorganizing staffing patterns, identify flexible personnel and organisation of work - ageing in place: explore options to keep person in place, promote slow relocation or try to prevent it, plan for the future. - giving time to adapt to change - Active mentoring during transition to retirement
Physical well-being	Health	- Maintaining physical health and fitness -Taking medications, - Avoiding health and safety hazards, - Ambulating and moving about - Obtaining health care services, learning how to access emergency services. - Maintaining a nutritious diet.	- ensure better health by providing exercises and nutritious foods: http://www.healthmattersprogram.org/products/; https://www.kennispleingehandicaptensector.nl/gezondheid - Treatment of physical issues: pain, insomnia, dehydration, infections, secretions, nausea, lack of appetite - Taking precautions to prevent choking and aspirating. - Fall prevention - Correct and early diagnosis and treatment by thorough review of medical, medication and behavioural history. - early for dementia, cardiovascular disease risk, chronic kidney disease – NTG-EDSD Early detection screening for dementia instrument (available in several languages): http://aadmd.org/ntg/screening Good physical environment, aids and adaptations provided for health problems/dementia. - Regular contact with GP or with

Domain of Quality of Life	Indicators	Support needs	Support activities/strategies
			healthcare resources leads to better participation in ColonCancerCheck Program. My Health Passport: (Spanish and English): Perkins, E.A. (2011) http://flfcic.fmhi.use.g.du/docs/FCIC_Health_Passport_Form_Typeable_English.pdf.
Material well-being	Financial status	Having enough financial resources Having pocket money Adequate accommodation for living Personal possessions, e.g. photos, furniture, clothes.. Needforadjustments	- Providing a living place in line with the wishes of the person, that is affordable, homely, comfortable and adjusted to the physical and mental needs. - providing aids, equipment and adaptations for physical changes, mobility devices, cognitive devices,… . - re-allocate or seek additional resources - re-organize staffing: identify flexible personnel, also seek staff with age care or medical experience - work together with elderly care; intersectoral cooperations - planning for the future: develop a financial and legal plan with the parents or other legal representatives, residential plans,…
Existential/spiritual well-being	End of life care Religion/spirituality	end-of-life care planning believes/religion	- Giving spiritual care to anxious elderly dying - Programmes/workshops that address knowledge about later life issues and end-of-life care planning - Honouring last wishes - have regular talks about end-of-life issues with the client End-of-life support: top tips, resources and good practice examples available here: https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

Class activity 6: supports

Use Unit 3 - template 3: Physical well-being and support

- Take the client in mind that you interviewed earlier with the QoL AAWID questionnaire.
- Using the table above as well as all information gathered on physical well-being and health of AAWID, describe his/her physical well-being (eating, physical exercise, physical health).
- What are his/her wishes
- Describe how intense and how often support is needed
- Write down the goals of the client (important to) and the goals of you as a support worker (important for)
- Describe the interventions needed to achieve the balanced goals and think about who besides yourself would need to be involved.
-

	Current situation	Client wishes	Support Intensity and frequency	What are his/her goals	What are your goals	Interventions
Eating Exercise health						

3.3.1.5 STEP 5: Who will give support?

A final but essential step in the clarifying phase is the formation of the support group. It is important that the person with ID chooses his/her own support group. A support group is ideally a diverse group of people (i.e. parents, family members, friends, support workers, etc.). The constellation of the group may vary depending on AAWID's chosen life goals and/or related support needs.

Some guidelines

- For the ISP process to succeed the facilitator should explicitly ask each member for their participation and inform them about their tasks.
- A support group carefully listens to what the person has to say and makes every effort to realize the person's dreams.
- A support group communicates openly with the person and if necessary meets on a regularly basis.

Keep in mind that the majority of AAWID rely on a very small to non-existing social network. On top of that, they often have to move away from home, or make a transition to another care facility. In such cases, unless AAWID decides differently, it is important that the facilitator also invites professionals from this new setting to the support group,.

When the support group is formed, it is the task of the facilitator to organise a first meeting, based upon the date and place put forward by the AAWID.

Class Activity 7: relationship cycle

Use unit 3 - template 4: Relationship cycle

Take the person you interviewed in mind and try to complete the relationship cycle. Think about who might be involved in supporting the person to achieve his/her wishes and goals. Who is missing? What could you do to expand the support group of the person.

3.3.2 PHASE II: Planning and implementing the ISP

Phase II (Planning) till Phase V (evaluation) is only for educators withEQF Level 6-8.

The process of planning is **quintessential** for an effective and efficient implementation of the ISP. Planning of ISP is a **group event** whilst maintaining **person-centredness** throughout the whole process.

People involved in phase II:**AAWID** + **coordinator** + **support group**

- The facilitator takes on the role of a **coordinator** which is responsible for the process of the ISP. He/she leads the meetings and always places the wishes of AAWID in the forefront of the conversations.
- In case of disagreements or disputes, the coordinator looks for the best compromise.
- He is also responsible for the implementation of the ISP and for monitoring AAWID's goals. When the goals can't be reached, the coordinator will keep searching for alternatives.
- When the facilitator is unable to take on the responsibility as coordinator, someone from the support group is probably the best suited to take on this role as he/she mostly knows the AAWID well and is able to advocate for him/her.

3.3.2.1 STEP 1: Gathering, organising and analysing all information

The coordinator gathers all information that was retrieved during phase I (QOL, support needs, priority goals, …) with the intend to develop well-founded goals and support needs, and assuring that no relevant information gets lost.

Tips

- ✓ By using an overview table, analyses and reports of the information becomes more accessible.
- ✓ Data can be organized within the framework of QoL facilitating holistic multidimensional and evidence-based practices.
- ✓ The table gives an overview of the different (input) data which is also linked to the output data, i.e. concrete goals that are put forward at the end of the process (left to right thinking).
- ✓ See the overview table annex … as an example of how to organise the data.

Note!

An ISerview table should always take into account that is reflects the wishes of the ID, the support goals and support needs. However, an overview table is in a sense also flexible as it is just an idea on how data can be organised. Each organisation can create its own table by either adding or removing columns.

See the table below. In the first 'column, the coordinator writes down all information that is gathered during step 1 and 2 of phase I. As leading principle she/he uses the different indicators and questions per QoL domain.The QoL AAWID score gives information about the objective QoL situation of AAWID. The satisfaction score is how the AAWID really feels about his/her situation (subjective score). The final box highlights the wishes of AAWID, what he/she wants or doesn't want for the future.

Table 3-2: Example of an overview table for the QoL domain self-determination

QoL domain	Self-determination
Instruments	QoL AAWID
Indicators	making daily life choices, future planning, ageing in place, …
Important information	In 2016, Greta suffered a major stroke and was unable to continue her work. When it became clear that her condition continued to deteriorate, mobile support was temporarily exchanged for periods of short stay in a specialized service for ID. It was suggested by her support workers that such a specialized residential setting would be the more appropriate living situation for Greta. However, Greta could not afford it as the allocated budgets – based on the situation before the stroke – did not allow her access to more costly residential care settings. Her support worker is currently applying for admission to an elderly home.
Score on the QoL AAWID	1
Satisfaction score QoL	2
Wishes	Unclear. Greta never expresses what she really wants, only gives socially desirable responses.

Afterwards, the coordinator analyses all information gathered in step 3 (support needs) of phase I and matches it with the QoL domains. He/she prioritises the support needs that are relevant to realise AAWID's wishes. The SIS, for example, distinguishes 4 types of support:

- Controlling/monitoring
- Verbal instructions and/or use of gestures
- Partiallyphysicalguidance
- Complete physicalguidance

Table 3-3: Example of an overview table for the QoL domain self-determination

QoL domain	Self-determination
Support needs	Greta needs support in learning how to make her own choices. Learn to understand her support needs and financial situation. Make a well-informed decision about her future living arrangements.
Type of support	Greta is able to learn with clear verbal instructions accompanied with visualisations. Supported decision making (supporters = Frida, friend of Greta and mobile nurse).
Frequency	Every day decisions Twice a week until she is able to make a well-informed decision.

3.3.2.2 STEP 2: Working together

The coordinator uses all the information that was gathered by the facilitator in phase I to organise the first meeting with AAWID and his/her support group. The aim of this meeting is to develop concrete support goals and to look for strategies that supports AAWID in realizing his wishes.

Full and equal membership is crucial to create an open dialogue. When opinions are conflicting, the coordinator looks for the best possible solution. If AAWID's wish is unrealisable, the support group still tries to look for possible alternatives.It is the group's responsibility to start from what is 'important to' the ageing adult with ID and find the right balance in what is 'important for' that person.

Guidelines for the meetings with the support group

- Let AAWID decide where, when and at what time the meeting should take place.
- AAWID should always be present at the meetings.
- AAWID decides when to pause or stop the meeting.
- All members of the support group are equals.
- AAWID's wishes are always at the forefront of the meeting.
- The coordinator uses the same language or communication.

- Someotherrules:
  - Always talk to AAWID as an adult.
  - Make eye contact when talking to someone.
  - Be positive about AAWID's aspirations.
  - Believe in AAWID and in his/her wishes.
  - Recognise difficulties and try to handle them constructively.
  - Throughout the meeting, ask AAWID if he/she understands what has been said.

Tips

- ✓ *Create a welcoming atmosphere during the meeting, e.g. bring some snacks and drinks to the meeting*
- ✓ *Play a game to get to know each other better,*

  Example 1: Let everyone take out their keys. Ask them to take one key that is very important to them. Give them a few minutes to think about the reason. Ask them to tell the story of the key to the rest of the group.
  Example 2: Give everyone a small piece of paper and something to write with. Ask everyone to write down 5 things about him-/herself. (e.g. green eyes, love to dance, have a dog, like French fries, brown hair). Let them first fold the piece of paper (show them how to do it) before putting it in a bag/pot. Shake the bag/pot. Open the bag and let each person draw one piece of paper. If someone draws his own piece of paper, let him/her draw a new paper. Let them guess who is the paper from…who do they recognise and why.

After getting to know each other, the coordinator gives an overview of the information gathered in phase I and ends by explaining AAWID's wishes. When several wishes need to be addressed, it is AAWID who decides which wish needs to be prioritized. However, if AAWID is unable to make that choice, or when he/she feels that all wishes are important, the coordinator goes through each QoL domain and together with the other members tries to achieve a supported decision, i.e. a decision that is in the best interest or known preferences of the person.

Note!

What to do if a person's wish is unrealistic?

When a person reveals an unrealistic dream about the future, it is imminent to reflect upon the following questions "why is this dream unrealizable?Is it due to limited capacities of the person or is it related to the restrictions of the services and the limitation in the supplies they offer.Or are the options of the support group limited?"

The first case points to an unrealistic and poor self-image of the person in question. Bursting his/her bubble will not help the person to make a more realistic dream. It is only with the help of supportive relationships and positive self-experiences that he/she will gain insight and eventually burst his/her own bubble.It is also the task of the support group to search for a good alternative. For instance, Greta dreams of living in her own house again but needs 24 hours care. The support group should try to find out why she likes her house so much. What for Greta is necessary to feel at home. Maybe she misses her things and her furniture, or the fact that she could be on her own. This information can help to look for alternatives, such as finding an apartment within a group home where she can put her own furniture and be on her own when she wants to be.

Finding good and valuable alternatives are also essential when the service providers have restrictions or limited supply. For instance, if the group home doesn't allow people to bring their own furniture, the support group could look for another affordable apartment within the elderly home or negotiate a minimum of furniture that might be allowed until she is able to move to a better place.

To conclude, it is imperative that all members of the support group acknowledge AAWID's dreams, openly discuss them and strive to find equivalent alternatives.

When the wishes of the person are clarified, the coordinator asks all members of the support group if they would like to add information that might be vital to the person's well-being (safety, health,…).Sometimes this might be vital medical information, such as epilepsy seizures caused by staring to long at a computer screen. Or about particular behavioural problems that might occur before these seizures are at play. All of these remarks and explanations are necessary to pursue AAWID's support goals.

QoL domain	Self-determination
Priority 1	Greta wants to life in a place of her own
Perspective of the support group	Greta needs 24 hours care and cannot afford to live on her own.

Note!

The overview-table is not exhaustive and does not comprise all AAWID's supports. The support goals that should be mentioned in the table are derived from the wishes of the AAWID. Information about his/her daily supports are equally important but are not mentioned in the ISP. However, it is advisable to clearly distinguish the 'support-plan developed by the educator on a day to day bases' and the ISP which only mentions the support goals needed to fulfil the AAWID's wishes. Keep in mind that this distinction does not result from a negative prejudice about the AAWID's capacities. It can be however imperative for the proper functioning of an organisation. For instance, Greta has no particular wish about her physical health. Yet, her physical health remains a very important support need that needs to be mentioned in the support-plan of the educator.

The role of the coordinator?

The strength and cooperation of the support group largely depends on the coordinator. Some tips to support the coordinator in his/her multifaceted job.

- ✓ **Why are we here?** Explain the goal of the meeting at the start of each meeting.
- ✓ **Review earlier goals:** Review the previously agreed strategies and ask members of the support group to highlight previously assigned task(s).
- ✓ **Highlight (forgotten) details:** Keep the information from phase I in mind and ask extra questions to the AAWID if needed.
- ✓ **Always focus on the AAWID:** In the event of disagreement, redirect the conversation and remind everyone of the AAWID's wishes and interests.
- ✓ **Work constructively and don't focus on the disability:** focus on the AAWID's talents and strengths**.**
- ✓ **Use posters:** posters or general overviews help to keep focus on what is important and enhances transparency; everyone is kept fully informed at all times.
- ✓ **Clarify responsibilities**: Clarify to each member of the support group the content of the strategy, how to implement the strategy, and determine the time-frame.
- ✓ **Summarise:** at the end of each meeting, the coordinator summarizes the discussions.
- ✓ **Report:** write down all the information necessary to develop the ISP and sent it to all members.

Note!

What to do when members of the support group have conflicting ideas?

It is the task of the coordinator to settle these differences, stimulate compromise and a common goal. When conflict occurs during the meetings, use the following person-centred planning problem-solving tips from (Holburn et al., 2007).

- **Be positive**: positivity stimulates and encourages others to be more positive.
- **Involve everyone**: try to get input from all members of the support group; explicitly ask the opinion of every member of the group.
- **Clarify information that is unclear**: explain difficult words/concepts; use visualisations.
- **Try to reach consensus:** situate the problem and explain positive and negative aspects; clarify the differences in perspectives to the entire group.
- **Don't let system barriers hold you back:** acknowledge the barriers in the system (policy – or organisation level) but avoid long discussions; look for alternative approaches to reach the goals.
- **Endorse participation:** give positive feedback to members of the support group when they share their thoughts and ideas on how to augment the wellbeing of AAWID.
- **Encourage innovation:** stimulate creative thinking and out-of-the-box solutions; use brainstorming techniques.

3.3.2.3 STEP 3: What are the supporting strategies?

In step 3 the coordinator, together with the AAWID and the support group, look for concrete supporting strategies in order to realize the AAWID's wishes. As in previous steps,it is important to involve all members of the support group because this will increase their overall commitment.

After reviewing all the relevant QoL information, the coordinator starts the conversation about specific support strategies. Schalock&Verdugo (2012) developed a list of specific support strategies. This list includes various forms of support that either are person-centred, system-oriented, or society-oriented.

This triple perspective maximizes the use and coordination of support possibilities, stimulates thinking and the creativity of the members of the support group and thus also promotes the personal outcomes (Schalock&Verdugo, 2012).*"Effective support strategies promote the development, independence, interests, and well-being of a person, and enhance the individual's functioning, participation within society, and engagement in life activities. By having ready access to what specific support strategies are, and their anticipated effect(s), support teams can align assessed support needs with specific support strategies and use this information as an essential part of supports planning and implementation".*

In the table below we provide a summary of seven widely used specific support strategies, along with a description of their components and purpose. This table is based on the international Delphi work of Lombardi, Chu, Schalock, &Claes (2017).

Table 3-4: Specific Support Strategies and Their Components and Purposes

Strategy	Components and purpose
Natural Supports	Building and maintaining support networks (e.g., family, friends, peers, colleagues), and fostering self-advocacy, friendships, community involvement, and social engagement.
Technology	Using assistive and information devices to enhance an individual's ability to communicate, maintain health and wellbeing, and to function successfully within his or her environment. Examples include communication aids, smart phones, electronic tablets/devices, medication dispensing devices, medical alert monitors, and speech recognition devices.
Prosthetics	Providing sensory aids and motoric assistance devices that support the body to undertake functions it cannot. Examples include wheelchairs, robotic arms or legs, special glasses/visual aids, hearing aids, and orthotic devices.
Education Across the Lifespan	Developing new skills and behaviours through behavioural techniques (e.g., modelling, manipulation of antecedents and consequences), task analysis, and education and training strategies such as Universal Design for Learning.
Reasonable Accommodation	Ensuring physical accessibility of buildings, transport, and work spaces; creating secure and predictable environments; and providing physical and other accommodations that allow individuals to negotiate their environments and carry out daily tasks.
Dignity and Respect	Enhancing social role status through community involvement, equal opportunity, recognition, appreciation, financial security, honours, personal goal setting, empowerment, and control of an individual supports plan.
Personal Strengths/Assets	Facilitating individual preferences, personal goals and interests, choice and decision making, motivation, skills and knowledge, positive attitudes and expectations, self-management strategies, and self-advocacy skills.

When looking at the situation of Greta, we are able to conclude the following:

Table 3-5: Example of an overview table for the QoL domain self-determination

QoL domain	Self-determination
Support strategies	
Who?	Frida = nurse who took care of Greta when she still lived alone Sam = her support worker at the elderly home crisis-unit
How?	Greta trusts Frida and sees her as her best friend. (natural support). Frida wants to help Greta understand why she can't live alone anymore. She also wants to support Frida in creating a place to be at the elderly home. Sam will use person centred planning techniques to help Greta in creating short-term goals and learn how to make her own choices. He will do this twice a week, each time for 30 minutes as this is the time-span that is still ok for Greta.

Tasks of thecoordinator:

- ✓ Reviews all potential support strategies
- ✓ Asks the members of the support group for possible alternative supports
- ✓ Asks who is prepared to take on a specific task
- ✓ Asks on a regular basis AAWID's opinion
- ✓ Asks the AAWID's approval of the chosen support strategy

3.3.2.4 STEP 4: Which are the supporting goals?

In step 4 the coordinator, together with the AAWID and his/her support group, formulates concrete supporting goals that are in line with the supporting strategies previously agreed upon. The coordinator must ensure that all supporting goals are concrete, well defined, clear, and unambiguous. Concrete goals are critical so that all members of the group know when goals have been reached, what objectives have been attained, and what progress has been made. Everyone knows what needs to be done so that they can achieve their desired results.

Applied to Greta's ISP:

QoL domain	Self-determination
Supporting goals	
Supporting goal 1	Frida comes to visit Greta ones a week and listens to what is important for Greta to make her feel at home.
Supporting goal 2	Frida brings pictures of Greta's old house and tries to find out which of the furniture is very important to Greta.
Supporting goal 3	Sam will use person centred planning techniques to help Greta in creating short-term goals and learn how to make her own choices. He will do this twice a week, each time for 30 minutes as this is the time-span that is still ok for Greta.
Date start goal 1	28 November 2020
Date realization goal 1	15 December 2020

3.3.2.5 STEP 5: Create an Individualized Support Plan

In an ISP, the support needs and future wishes of the AAWID are only a part of the plan. ISP may also describe a person's past and current situation. The ISP is the output of the agreements between the AAWID and the service provider about the supporting goals and –strategies. Besides specific agreements concerning the supporting goals, there are no guidelines about the content of the plan. Each plan is personal and unique. The information that is mentioned in the ISP is in itself determined by the AAWID him-/herself in agreement with the coordinator. That is why some ISP are one page only whilst others count several pages.

There are however some guidelines about the agreements made between the AAWID and his/her support worker. The agreements:

- are based on the capabilities, disabilities, wishes and needs of the AAWID
- focus on maintaining or enhancing the QoL
- incorporate the support strategies
- indicate who is responsible for the coordination and monitoring of the ISP
- mention all persons involved
- indicate who is responsible for the realisation of the support goals

The AAWID possesses his/her own ISP. Conditions are:

- AAWID determines who reads the ISP
- AAWID keeps his/her own ISP
- AAWID knows where else the ISP is stored
- AAWID is able to determine what information needs to be kept private.

Note!

What if the AAWID doesn't want to have a ISP?

Respect AAWID's choice. However, it remains important to write down the information gathered from phase I and II in the supports-plan of the educator because the information might still crucial for the AAWID's daily support.

3.3.3 PHASE III: Monitoring

3.3.3.1 STEP 1: Monitoring progress of the support goals

It is the role of the coordinator to evaluate whether the goals of the ISP have been achieved. If this is not the case, the coordinator has to explore plausible explanations and if necessary redefine the goals.It is essential for the coordinator to continuously monitor the ISP implementation progress.

QoL domain	Self-determination
Supporting goals	
Supporting goal 1	Frida comes to visit Greta ones a week and listens to what is important for Greta to make her feel at home.
Supporting goal 2	Frida brings pictures of Greta's old house and tries to find out which of the furniture is very important to Greta.
Supporting goal 3	Sam will use person centred planning techniques to help Greta in creating short-term goals and learn how to make her own choices. He will do this twice a week, each time for 30 minutes as this is the time-span that is still ok for Greta.
Date start goal 3	15 March 2020
Date realization goal 3	
Reason why goal 3 was not achieved	Goal 3 is not realized because Sam no longer works at the elderly home and nobody else is currently trained in person-centred planning techniques.
Maintain or change goal?	Maintain goal and train Maria (nurse that supports Greta at the nursing home) in person-centred planning techniques.
Financial cost	200 €

3.3.3.2 STEP 2: Monitoring the process

Process monitoring activities must be embedded within a continuous quality improvement cycle: data collection must focus on personal outcomes that are important to the AAWID with intellectual and developmental disabilities, and the results must be translated into actions. Some core elements/ questions about the planning process, derived from a review study on existing measures (Martin, Ouellette-Kuntz, Cobigo and Ashworth, 2012) can be helpful to monitor the ISP process.

- The AAWID is involved in selecting the timing and location of the meeting
- The AAWID chooses who is involved
- The AAWID is involved in discussions
- The AAWID has the opportunity to make meaningful choices

- The AAWID's natural supports are encouraged to participate in discussions
- There is trust among the members of the planning/ support group
- The support group works collaboratively and with respect
- Focuses on the AAWID's strengths, abilities, and aspirations
- Identifies clear actions to achieve the goals in the plan
- Identifies supports within and beyond those of the provider agency that are needed to achieve the goals in the plan
- The AAWID's services, supports, and day-to-day activities are adapted to ensure that they are in sync with the goals identified in the plan
- Periodic evaluation of actions and outcomes
- Ongoing commitment to revisiting actions and outcomes
- The person is happy or satisfied with progress made toward identified goals

3.3.4 PHASE IV: Evaluation

A year or two after starting with the ISP, the coordinator investigates the impact of the independent variables (i.e. personal characteristics of the AAWID, the support goals and support strategies) on the dependent variables (personal outcomes of the AAWID). In other words, he/she evaluates to what degree the personal outcomes (QoL domains & support needs) have been influenced by the realization of the support goals and -strategies.

How? The facilitator uses the same instruments as in phase I to find out more about the current QoL and support-needs of the AAWID. Did the QoL of AAWID effectively improve? Which domains improved? Is this improvement related to the support goals and - strategies? If not, how come? Did AAWID change his/her opinion?

References unit 3

This unit is largely based on Broekaert, R. Claes, C. &Vandevelde, S. Samenaan de slag. Naarvolwaardigpartnerschap in het persoonsgerichteondersteuningsproces.[Working Together. Towards a full partnership in the process of person-centred planning] Gent: Academia Press; 2014

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UNIT 4

THE MNAM INTERACTIVE TRAINING PLATFORM

4.1 Introduction

The rapid development and democratization of technologies has enabled the implementation of learning programs with a strong influence of Information and Communications Technologies (ICTs). The educational tool developed in TRIADE 2.0 project is backed up by an online platform which enables an interactive navigation through the factors, units and exercises. The aim of this unit is to introduce and teach support workers/educators on how to effectively use the My New Ageing Me (MNAM) platform. Unit 4 contains two main conceptual parts: The first (4.2 and 4.3) constitutes a theoretical approach to the use of ICTs to improve the QoL and promote the inclusion of AAWID based on latest research, the second (4.4) are the instructions manual to use the MNAM platform from the perspective of the educator.

The American Telemedicine Association (ATA) defines *Telemedicine* as a variety of applications and services that use different communication channels: two-way video, email, smart phones, wireless tools, and other forms of telecommunications technology. Consultations through videoconferencing, remote image transmission and analysis, internet health information, remote monitoring and analysis of vital signs are considered part of telemedicine, but its definition also includes the continuation of medical and assistive education. Due to the high heterogeneity of applications and services, the Centre for Connected Health Policy (CCHP) adopts a general definition: "Telemedicine is not a specific service, but a collection of means to improve health education care and provision".

Within these definitions, the TRIADE 2.0 MNAM platform is conceived to provide teaching support and resources through the Internet, using a web portal that can be accessed anywhere, anytime and from any device (Personal Computer, Laptop, Tablet and Smartphone) regardless the operative system (Windows, iOS or Linux).

Figure 4-1: TRIADE 2.0 platform pedagogical structure.

The information on the MNAM Platform is organized in the 3 factors of the model of Quality of Life studied in the unit 2 of this workbook. Each factor has a list of didactic units and the corresponding practical exercises and activities.

4.2 The role of ICTs supporting AAWID care

Today we are living in a society where information and communication technology (ICT) can support empowerment and social participation, however AAWID with mild-to-moderate intellectual disability are at risk for marginalization by the digital divide. Availability to ICT is highlighted as a human right in The Convention on the Rights of Persons with Disabilities [1] but rapid technological development and the changes it brings make ICT even more challenging [2].

There is a significant gap in the use and ownership of ICTs and the Internet between people living in residential homes, such as people with intellectual disability, and the rest of the population. Previous research has focused on interventions to increase and maintain knowledge and use of ICTs, and moreover it has been shown that daily support from staff or others is crucial to facilitate the access ICTs. Organizations with clear goals related to ICT increase service-user participation in ICT-related activities. A person with mild-to-moderate intellectual disability benefits from an organization that provides support from all levels, from decision and policymakers to the operational staff. The organization needs to ensure that operational staff members have adequate supporting skills and that training is offered when such skills are lacking [3,4].

AAWID may experience major difficulties engaging independently in functional daily activities which turns in the need to define strategies to help them reach a more active and functional role within their contexts. Staff resources are known to effectively support AAWID, but extending its responsibilities and assigning tasks which are beyond their knowledge may not be feasible nor desirable. Thus, a wide variety of ICT bases supporting tools have been proposed to increase AAWID activity engagement. Basic tools consist of interactive booklets with pictorial representations in a tablet or a desktop application with a beamer. Other include advanced technologies for voice recording, simplified interfaces or body-tracking devices to guide users step-by-step and advise about the performance of the activities. Studies assessing the effectiveness of the afore mentioned tools have reported encouraging results, that is, people appeared generally capable of using the tools to carry out multi step activities independently [5].

Recent studies conclude that there is a lack of organizational support and comprehensive strategies for the use of ICT in social care for people with intellectual disability. A survey over 79 social care centres from municipalities in Sweden found that organizational support only exists to a limited extent, and the majority of had very little or no organizational support at all for the use of ICT by adults with intellectual disability. There is a strong need to support and increase the knowledge on how to use ICT tools by AAWID but, more specially by the staff.

4.3 Types of ICTs

ICTs are strong tools to support the training of educators and the activities of AAWID. It is important to remark that the ICTs are not useful by themselves and should be equipped with specific software especially prepared for supporting the training and the activities. In this chapter we refer to the ICTs as the visual-tangible devices (hardware) such as smartphones, tablets and personal computers with touch interfaces, other type of visual interfaces such as screens without touching interface, beamers, sensors and actuators and also to the applications (software) used for implementing the educational and evaluation programs such as tablet apps, virtual reality games and other programs in a computer.

A paradigmatic example is the Stimulus software[1], for the cognitive stimulation and rehabilitation of people with ID. Stimulus contains a set of interactive exercise to train a wide range of cognitive processes. All the activities are classified around functional areas (e.g.: attention, perception, working memory, among others) and are meant to be used in tablets and personal computers.

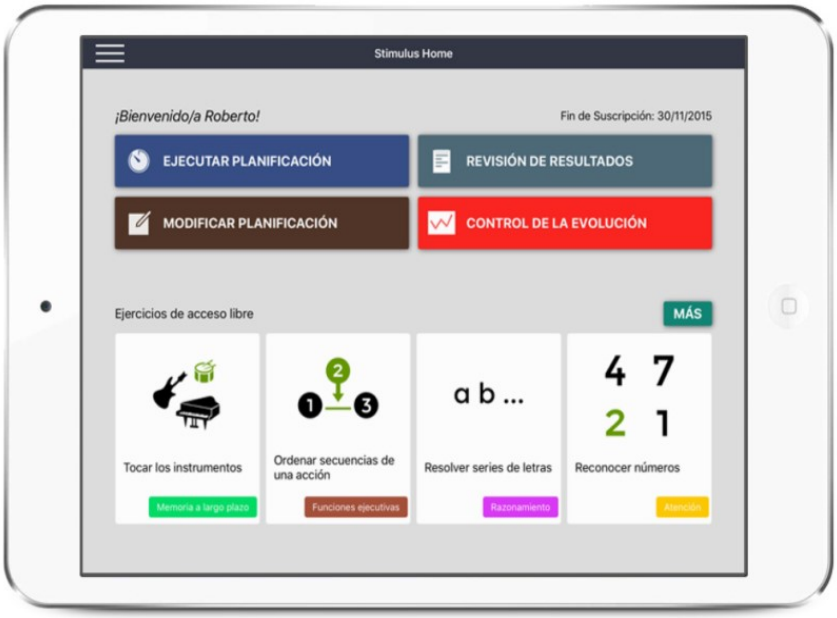

Figure 4-2: Stimulus software screenshot.

Stimulus allows accessing to the description of exercises, recording and monitoring the results of the exercises and organize training activities. Up to date the software is only available in Spanish and can be used under payment license.

[1] https://stimuluspro.com/

There are several investigations that are being carried out, in the field of health, about how to improve the quality of life of people who suffer from some intellectual disability with ICTs. All of them converge in the use, among others, of virtual reality as a means to improve and treat many aspects of life in these people. Virtual reality could be defined as a system that generates a perceptual reality, through electronic systems in real time, allowing the user to experience a feeling of being within the fictitious space.

In its beginnings, the application of virtual reality demonstrated its usefulness in the field of Neuropsychology. Numerous studies support its efficacy in patients with some type of Nervous System dysfunction, such as individuals with brain damage secondary to trauma, and even in patients who showed signs of hyperactivity, thus positioning itself as a highly beneficial technological tool for medical applications.

Currently, the most recent applications of virtual reality are being focused on simulating everyday situations or environments, such as taking the subway, going to the supermarket or heading to the bank, etc., demonstrating its effectiveness as a way of learning [6]. One of the examples from this study showed a group of people who had to learn to cook new dishes never prepared by them. Users had to cook them in a virtual reality simulation, in front of another group whose teaching was in person using manuals or video tutorials. The results showed how people who learned through virtual reality managed to make the dishes more accurately. This can later be generalized in real settings to train people with intellectual disabilities to face new situations and be prepared to face them in a normal way.

Another benefit that virtual reality brings to people with intellectual disabilities is seen in studies where this tool has been used to simulate daily activities and allow them to practice in stress-free situations and in a controlled environment. Virtual reality gives people with intellectual disabilities a sense of control during their learning and also has an incentive value for all the people who use it, increasing their self-esteem and sense of competence. This can also be extrapolated, for example, to the recreation of situations that may have caused trauma for a person, being able to overcome it with ease and without the stress of the consequences of reality.

Large associations such as ALEH [aleh-israel.es], the largest network of centres for people with disabilities in Israel, have also opted for virtual reality to enable children to enjoy new experiences. In this association, not only virtual reality is applied for teaching or developing basic activities, but it is also applied for the enjoyment of the little ones in many other activities, which due to their disability is very difficult to carry out, thus providing the

maximum immersion in each of these activities, maximizing emotions and enjoying each one of them.

Virtual reality is a very effective solution but it is not within everyone's reach. It requires high-end electronic systems and installation of programs that may not be easily accessible. For this reason, many people turn to traditional computers to develop programs that have the same objective that virtual reality has, to improve the lives of others. This is the case of a study carried out by two national universities, the Complutense University of Madrid and the Francisco de Vitoria University. Both universities have developed a video game called Downtown, a subway experience [7].

Downtown is a video game oriented to the use of adults between 18 and 45 years old with medium and severe intellectual disabilities. The objective of this video game is to train these people to take the subway and travel alone as if it were real life. Downtown doe not only train participants to choose the best route when taking the subway or going from station to station, it also includes puzzles and sub-missions that help players improve their basic day-to-day skills independently.

Although these types of video games can apparently provide benefits to people with intellectual disabilities, some studies report some limitations. Currently there are not enough studies that can guarantee that this types of video games are valid for people with intellectual disabilities, but they do show that they are an ideal educational tool to motivate and engage participants.

Although these types of video games can apparently provide benefits to people with intellectual disabilities, not all are advantages. Currently there are not enough studies that can guarantee that this type of video games are valid for people with intellectual disabilities, but they do show that they are an ideal educational tool to motivate and engage participants. It should be noted that for a forceful effectiveness in all users who demand this type of video games, it is necessary to know that these should be personally designed for each one of them, since not all intellectual disabilities have all their deficiencies in an equitable way.

Mobile phones and smart watches are also an alternative to support the training of educators and implementation of cognitive-behavioural therapies. A study by Giulio E. Lancioni [5] explains how a group of people with sensory and intellectual disabilities are provided with mobile phones specially designed for them, and use it to carry out daily activities at acceptable times.

The study consisted of two groups of four people, in which the members of the first group additionally had visual impairment and the second group who had hearing impairment. The activities to be carried out were daily activities such as preparing coffee in the morning, picking up the bathroom, cooking, making the bed, etc. All of these activities had predefined times to be carried out and were divided between 15 to 20 steps to complete.

The mobile phone that was used for the development of the study was the Samsung Galaxy A3 in combination with functions integrated into the mobile phone such as Bluetooth connectivity, alarm and multimedia players of the phone. On the mobile phones of the participants, audio and visual instructions were reproduced when an activity started or ended and during the development of the instructions to follow to carry out the activity were displayed.

People with mild or mild sensory and intellectual disabilities were able to fend for themselves with the help of smartphones and meet the objectives established prior to the evaluation of the study activities. Also, thanks to the audio and video tools provided by the phones, they can serve as an instructional tool regardless of the disability that arises. In short, despite the fact that the number of participants in the study was not very large, the results gave people who carried out the proposed activities with the mobile phone greater performance and efficiency. These participants were able to complete most of the activities in reasonable time and without difficulties with the support of ICTs.

The versatility of mobile phones, the easy access available and the competitive prices that technology currently offers, make mobile phones a great choice when developing educational, training or rehabilitation systems for people with sensory and intellectual disabilities. Another example of the application of ICTs to support the autonomy of people with intellectual disabilities is the AssistT-TASK app [8], developed by the *Universidad Autónoma de Madrid* and the University of Science and Technology of Norway. This fully functional application establishes a task-by-task learning method to carry out activities with autonomy in the private environment, such as at home or at work. Also, and because the choice of tasks can be somewhat complicated and not very intuitive, the app is capable of starting an activity simply by reading a QR code that could be available in sheets of paper or stickers in the wall. It is not so strange that in the same way that there are QR codes for information notes in public places or QR codes that provide us with a web address to write a review of a place we have visited, they exist to facilitate tasks for people with disabilities or someone else psychic impairment.

AssisT-IN is an updated version of the previous app designed for closed environments such as workplaces or centres that we visit daily, such as schools or teaching schools. A challenge that all of us face when we first access a job or join a new centre is that of adaptation. Being able to adapt and learn in a short time is something that can cost us all and especially those with intellectual disabilities. Those who are not yet used to these new places require staff from the centre to guide them through their adaptation period, which can lead to a feeling of dependency to move through the day care centre. AssisT-IN is based on the same concept that governs the previously described application. Users with the application installed scan QR codes that will provide step-by-step instructions to get to different places in the building. The instructions displayed on the screen of mobile phones are both visuals, landmarks such as images of doors, hallways, etc ... as arrows indicating the way forward. The results obtained when testing this application with people with intellectual disabilities in a real environment were very positive. From a sample of 14 people, all managed to get to the places he indicated in completely unknown environments.

Beyond the mobility into buildings, the AssisT-OUT app provides navigation to move outdoors, but this time it is needed to set a target destination. This application is adapted to the user in terms of calculating the best route combined with a simple graphical interface. The system calculates the route showing the instructions to follow the path and introducing photographs of the places of reference that can be seen when following these paths. In addition, AssisT-OUT also introduces GPS location and sound alarms to notify us of our relative position with respect to the following indication.

Finally, in the crossroad of virtual reality and the use of apps, there are other type of ICTs which have also been very effective in the field of educational tasks, such as the robots. Different studies confirm that the use of robots (humanoids) to help people with intellectual disabilities can be beneficial in areas such as psychomotricity or oral communication. This is the case of NAO [9] a small, humanoid, autonomous robot, designed by the SoftBank Robotics company, primarily intended for social development and oral communication with people. The robot can be programmed with a code-free application and includes peripherals such as a touch screen, speakers, microphones, video cameras, and even functional hands to grip objects. NAO is capable of mediating the dialogues that are established between people by reproducing their own voice, acting as if they were an oral instructor or mediator even with several students at the same time.

To conclude, although it is necessary more research in this area, the applications of ICTs for supporting the development of people with intellectual disabilities indicates that the use of technology for learning and developing basic skills of these people is crucial and has great benefits such as increased autonomy and independence.

4.4 MNAM platform: contents and structure

The MNAM Platform is composed by 5 main modules and 3 specific pages:

- Landing Page: offers basic information about the project and major descriptors of the structure of the training materials and the course methodology. This page should contain project official identifications, funding statement and the disclosure.
-

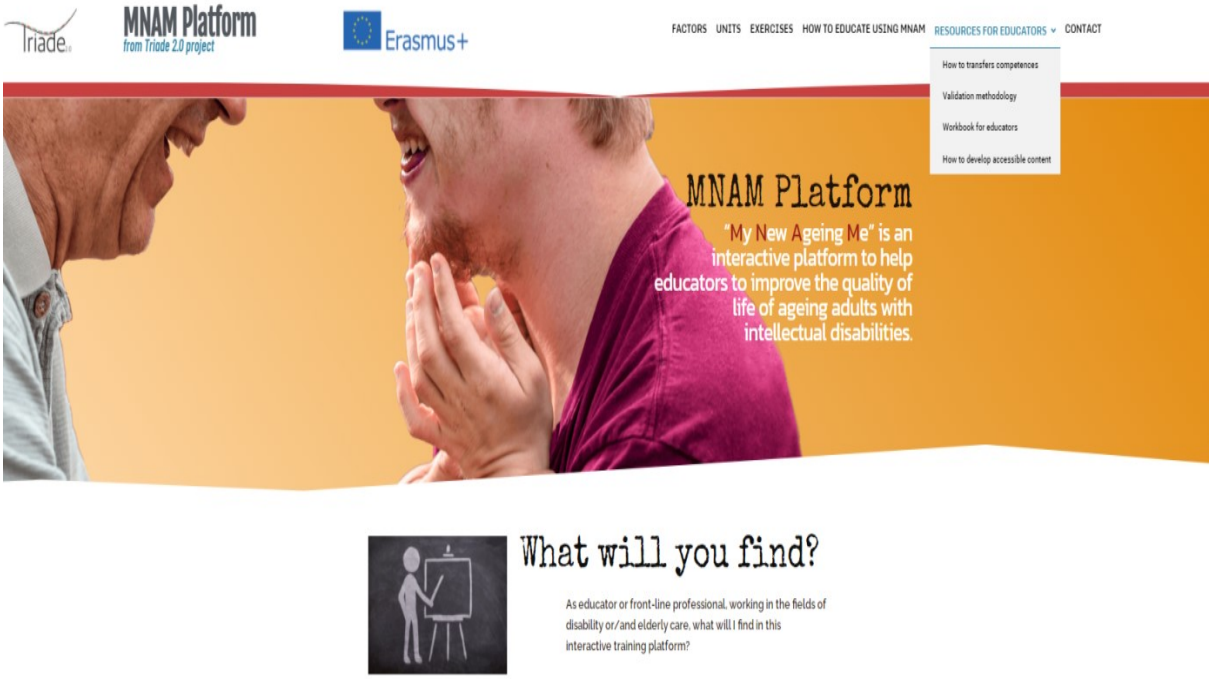

Figure 4-3: TRIADE 2.0 landing page.

- Factors: the main access to inform about the three factors considered in the training course. This page displays in friendly way the title of each factor and a short description. Each factor is linked to the corresponding Factor page.
- Units: List of the 14 Units in the training program. Each unit is identified with a text box indicating the factor to which it belongs. Each unit links to the Unit page.
- Exercises: Direct access to the exercises, classified according to the units of the course. The page displays the 64 activities/exercises and each of them is identified with a numerical code X.Y, in which X is the unit and Y is the exercise number.

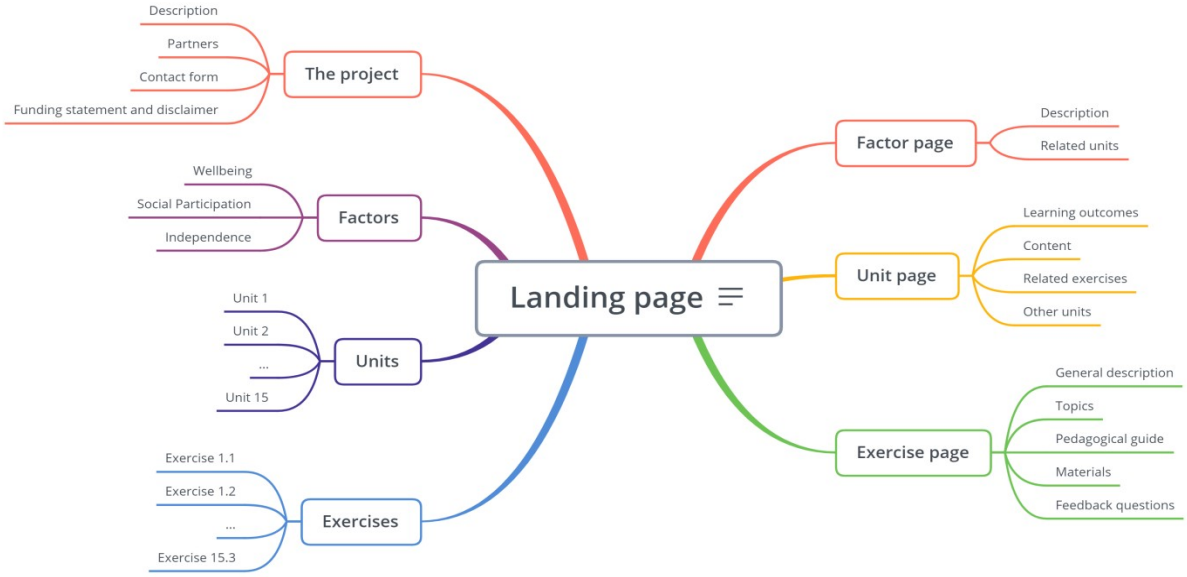

Figure 4-4: TRIADE 2.0 Platform structure.

- Factor page: The descriptor page of the factor, containing general information about the factor and links to the related units.

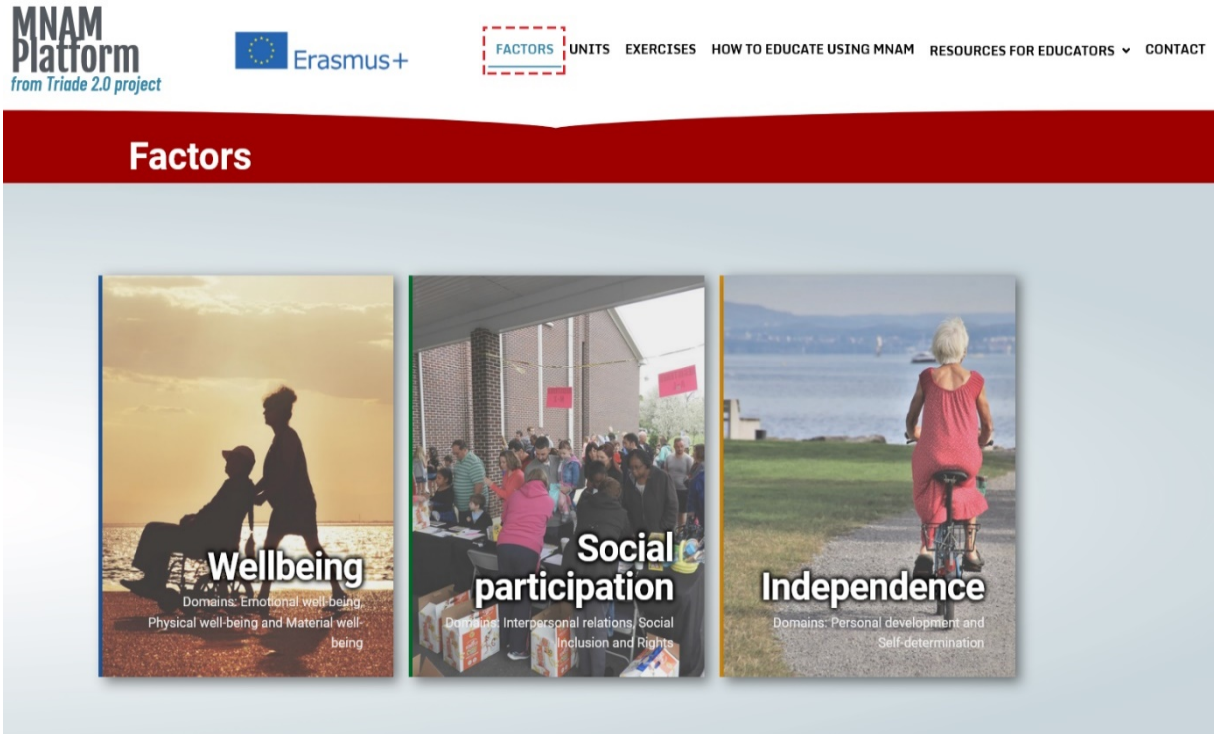

Figure 4-5: TRIADE 2.0 Factor page.

- Unit page: The descriptor of the unit. The page has three main parts referred to the learning outcomes of the unit (knowledge and skills), the content of the unit and related exercises. At the bottom, there is a direct link to other units of the same factor.

Figure 4-6: TRIADE 2.0 Unit page.

Figure 4-7: TRIADE 2.0 unit 1 page.

- Exercise page: The descriptor of the exercise and a pedagogical guide to implement the exercise with the provided materials.

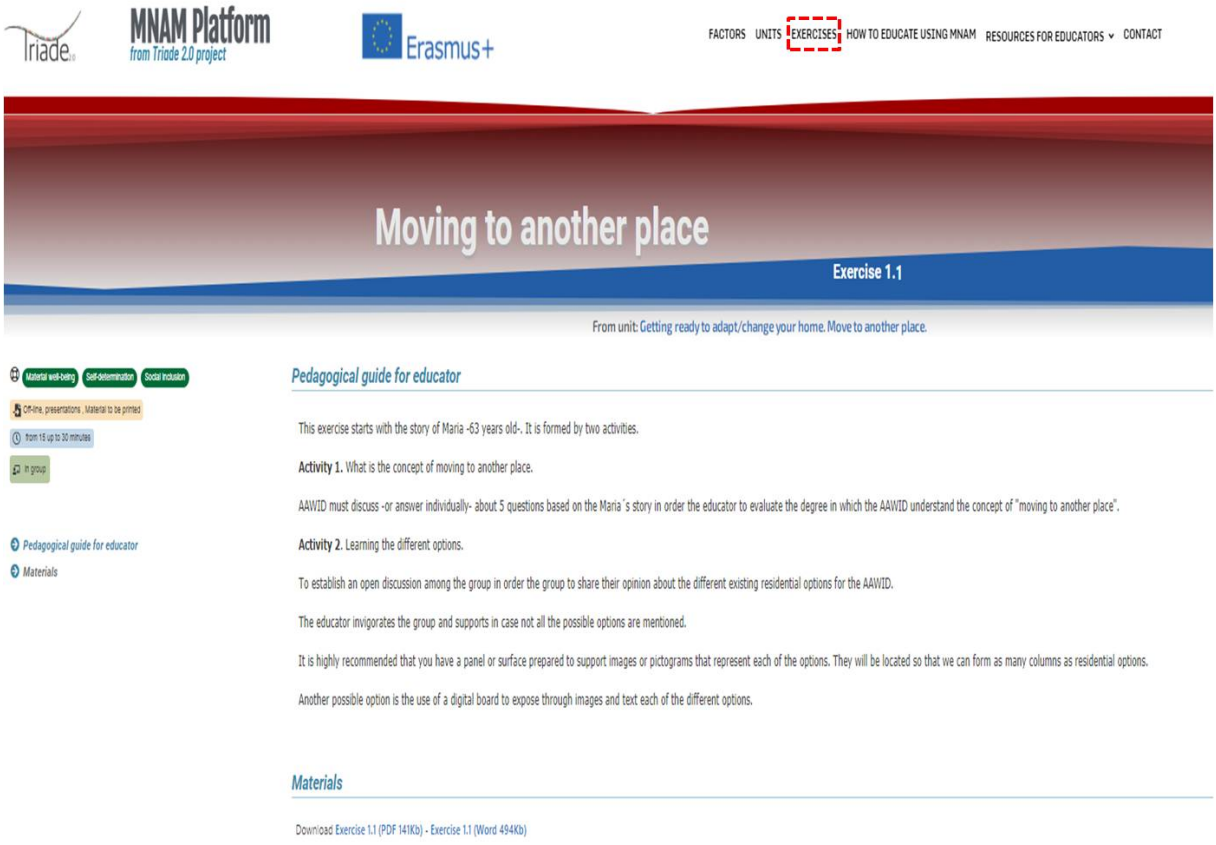

Figure 4-8: TRIADE 2.0 Exercise 1.1 page.

4.4.1 Landing page

A landing page is a standalone web page created specifically for the purposes of a marketing or advertising campaign. It's where a visitor "lands" when they have clicked on a given link (through web search or direct recommendation). The MNAM Platform landing page appears when the user browses the url: https://triade.webs.upv.es/t20.

Landing pages are usually designed with a single focused objective – known as a Call to Action (CTA). This simplicity is what makes landing pages the best option for increasing the conversion rates of dissemination campaigns and lowering the cost of acquiring a lead or sale.

To fully understand the difference between a landing page, and the other pages such as your homepage, it is important to consider the differences between organic search traffic and paid

search traffic. For the purposes of this document we will present the components of the landing page.

This page offers as much information as possible in small "pills" to encourage browsing the rest of the site. At the top of the page, there is a header that will be repeated in the rest of the pages and shows:

- project/platform logo
- Name of the platform project
- Erasmus+ logo
- Basic web navigation menu.

The rest of the content of the sections of the page presents:

- a descriptive sentence of the project
- a brief description of the project objectives
- description of the main structure of the information on the website: factors, unit, exercises, how to use the platform and several resources for the educators.
- a list of the project partners with their respective links
- a brief contact form for those interested in the project

The final section is a common footer on all pages showing the copyright and the project code and the logo of the European funding.

Educators can consult the Landing page for general information purposes, but to access to the educational resources, they should access to one of the direct links to the Factors/Units/Exercises in the top and the middle of the page.

These links allow accessing to the list of Factors, Units and Exercises, but they do not feature direct access to a specific Factor, a specific Unit nor to a specific Exercise.

4.4.2 Factors

The first section is devoted to the Factors of the training program. Factors stand as the high-level classification of the Units and the Exercises and may constitute the baseline gateway for educators to access to the information contained in the platform.

The user may select the factors from the links in the Landing Page, and then will be guided to the screen of the picture. In this first page, the user can see the three factors with a succinct description, and then click over one of them to access to the Factor page.

Figure 4-9: Figure 4.9. TRIADE 2.0 Factor page.

The Factor page contains a deeper description of the factor itself, so that the educator can learn know more about the implications and considerations of each of the factors in the training program: Wellbeing, Social Participation and Independence.

In this page, each factor provides a direct link to the corresponding units in the right menu.

Figure 4-10: Figure 4.10. TRIADE 2.0. Factor Wellbeing and related units.

4.4.3 Units

Units are the topics of the training program in which the theoretical concepts are developed. As mentioned, every unit belongs to one of the three factors, however, to ease the navigation the units can be accessed directly from the link in the landing page. Another way to access to the units is by using the Factor page. If the user selects the link from the landing page he/she will see a grid with links and descriptors of the 15 Units that build up the training program.

The user can identify the Unit numeric code, the title and also the Factor it belongs to. Furthermore, the units featuring practical exercises are marked with a symbol . On its current version all the activities feature practical exercises. By clicking over the box of the unit, the browser will open the Unit page, which is entirely devoted to the Unit details.

Figure 4-11: Names of the platform units classified by factors.

The upper part of the Unit Page is devoted to the title and a short summary of the Unit. It also has the previous indicators related to the exercises and the corresponding Factor.

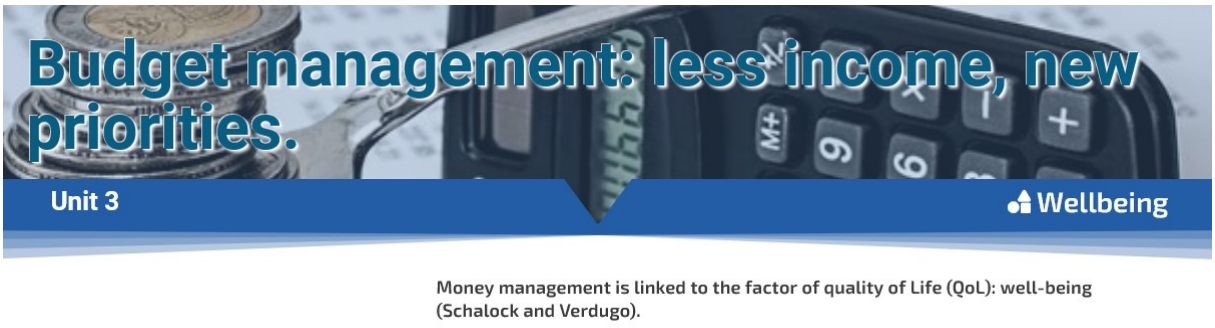

Figure 4-12: Upper part of unit 3.

Below the header, the page shows the complete descriptors of the units, which are the Learning Outcomes in terms of the knowledge objects and the corresponding skills that will be developed in the Unit. After this summary table, the page shows the actual content of the unit in plain texts and pictures.

The exercises corresponding to the Unit are listed in the right side of the Unit page. Each exercise is a link that leads to the Exercises page.

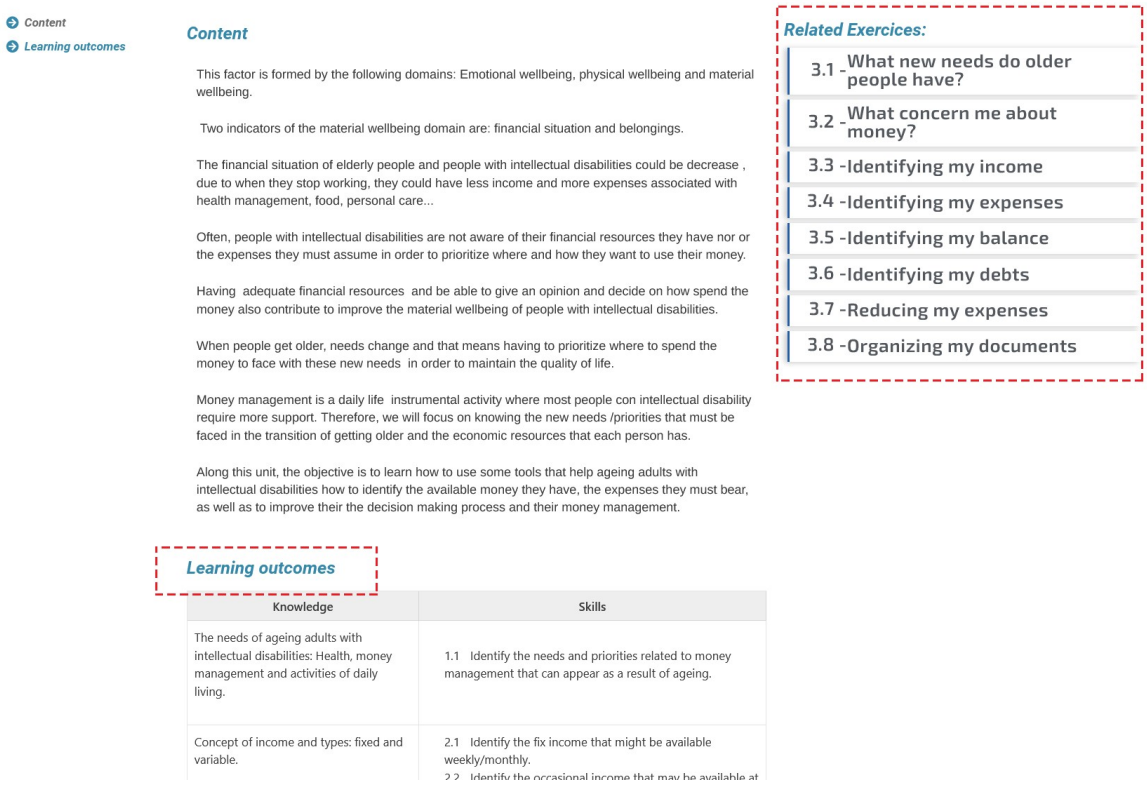

Figure 4-13: Unit page: content, learning outcomes and related exercises.

At the bottom of the Unit page there is a referral to other units of the same factor.

Figure 4-14: Bottom of the Unit page.

4.4.4 Exercises

Exercises belong to a specific Unit, which at the same time is linked to a Factor. The direct access to the Exercises from the landing page leads to the general view of all the exercises, sorted by the Unit identifier.

Figure 4-15: General view of the exercise page

Exercises can be accessed directly from this page, although the regular navigation path is from the Units or from the Factors pages.

Once the user clicks over an exercise the browser shows the exercise page. The exercise page is headed by the title of the exercise and the related Unit.

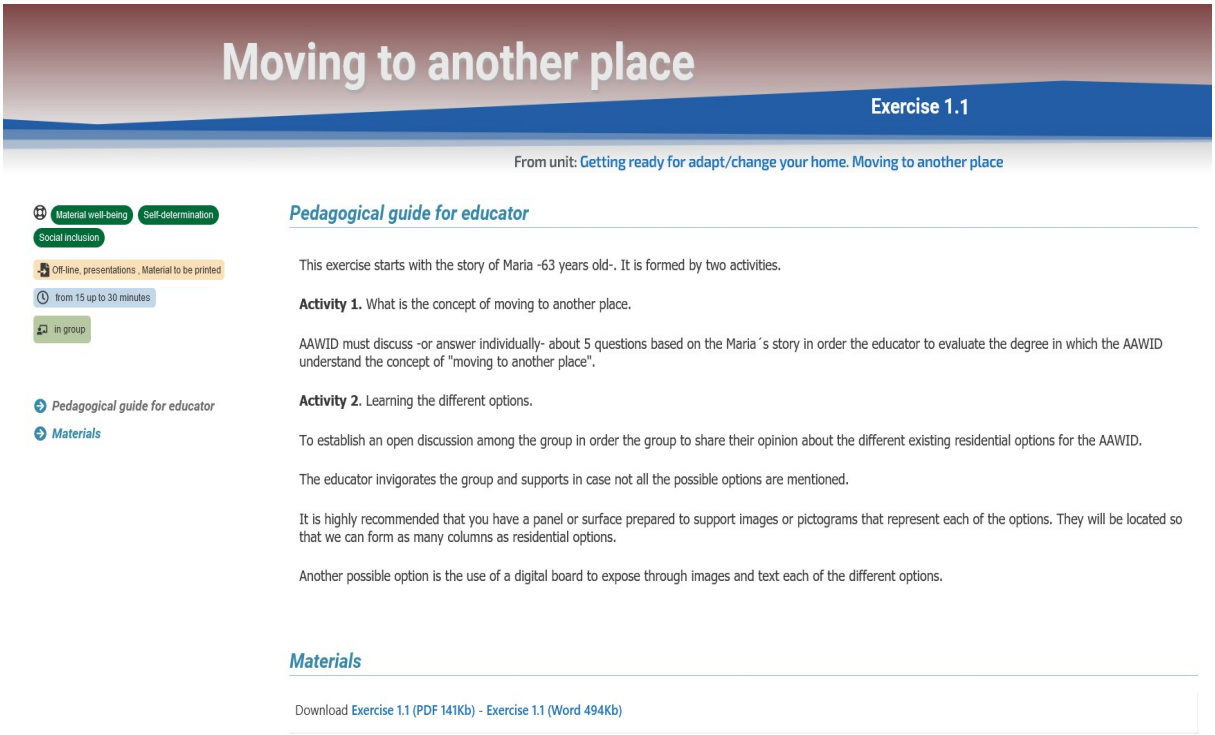

Figure 4-16: Exercise 1.1. page: pedagogical guide and materials to carry out the exercise.

All the exercises have the same structure:

- A pedagogical guide with instructions on how to develop the exercise.
- The materials -exercise- to be used by the educator.

Some of the exercises will include multimedia materials, such as a PDF document, a picture, working sheets or a video to support the educator in the implementation of the exercise.

4.5 MNAM platform pedagogical purpose: How to use it.

The MNAM Platform provides 64 exercises and pedagogical instructions to educators in order to improve the social inclusion and/or Quality of Life of ageing adults with intellectual disabilities (AAWID). In addition, the platform indicates the dimensions of the model of QoL upon which the exercises were developed.

Table 4-1: Name of the exercises and Quality of Life dimensions

Unit	Exercises	QOL domains
1.	**Getting ready to adapt/change your home. Move to another place.**	
1	1.1.Moving to another place	Material well-being, self-determination, social inclusion
2	1.2. What should we take into account when deciding where we will live when we are older?	Personal development, self-determination
3	1.3. What are the advantages of each of the different residential options?	Personal development, self-determination
4	1.4. Which residential option suits my interests and needs best? (My future residence).	Personal development, self-determination
5	1.5. Adapting the home. What is the best option.	Personal development, self-determination
2	**Adapting equipment and assistive technology**	
6	2.1. Difficulties in the activities of the daily living.	Physical well-being
7	2.2. The adapted environments.	Physical well-being
8	2.3. My support products (walker, hearing aid…)	Personal development, self-determination
9	2.4.Helping Maria to choose her support products.	Physical well-being
10	2.5. Matching assistive technology with its usefulness.	Physical well-being
11	2.6. True/False questions about adaptation, support products and assistive technology.	Physical well-being, personal development
3	**Budget management: less income, new priorities**	
12	3.1. What new needs older people have?	Material well-being
13	3.2. What concerns me about money?	Material well-being
14	3.3. Identifying my income	Material well-being, personal development
15	3.4. Identifying my expenses	Material well-being, personal development
16	3.5. Identifying my balance	Material well-being, personal development
17	3.6. Identifying my debts	Material well-being, personal development
18	3.7. Reducing my expenses	Material well-being, personal development
19	3.8. Organizing my documents	Material well-being, personal development
4	**Optimizing health: physical activity and a healthy lifestyle**	
20	4.1. Improving Maria's health	Physical well-being
21	4.2. Playing with the food pyramid	Physical well-being
22	4.3. Physical activity and its benefits	Physical well-being
23	4.4. True or false about healthy ageing	Physical well-being
5	**Being aware of the changes related to ageing**	
24	5.1. What does it mean ageing to you?	Emotional and existential
25	5.2. What does it happen when we get older?	Physical well-being
26	5.3. Ageing Concepts relation	Physical well-being
27	5.4. Quiz about ageing changes	Physical well-being
28	5.5. Open debate about psychosocial changes	Emotional and existential well-being
6	**Safety: prevention of abuse**	
29	6.1. Concept of abuse and types	Rights, emotional and physical well-being
30	6.2. Physical abuse	Rights, emotional and physical
31	6.3. Psychological abuse	Rights, emotional and physical
32	6.4. Economic abuse	Rights, emotional and material
33	6.5. Sexual abuse	Rights, emotional and physical
34	6.6. Abuse of rights	Rights, emotional and physical
35	6.7. How to respond to an abusive situation	Rights, emotional and physical
7	**Social connectness: keeping in touch with family and friends**	
36	7.1. Who is important in my life?	Interpersonal relationship

Unit	Exercises	QOL domains
37	7.2. Ways to reconnect or stay in touch.	Interpersonal relationship
38	7.3. My plan to reconnect or stay in touch	Interpersonal relationship
8	**Active ageing Postretirement working – or leisure activities in the community**	
39	8.1. Retirement	Social inclusion, personal development
40	8.2. Work & Leisure	Social inclusion
41	8.3. My dream retirement plan	Social inclusion, personal development, self-determination
9	**Social engagement: helping others and contributing to society**	
42	9.1. The notion of "having a social role to play"	Social inclusion
43	9.2. The little helper	Social inclusion, personal development
44	9.3. Social roles that are important to me	Social inclusion, personal development, self-determination
10	**Social media**	
45	10.1. Using internet and social media	Social inclusion, personal development
46	10.2. Search for information on the Internet	Social inclusion, personal development
47	10.3. Safe use of the Internet	Social inclusion, personal development
11	**Learning about your rights**	
48	11.1. What are my rights?	Self-determination & rights
49	11.2. My rights are about to be violated – what to do?	Self-determination & rights
50	11.3. Actions for my rights protection.	Self-determination & rights
51	11.4. How do my rights work for me?	Self-determination & rights
12	**Who are the persons important to me?**	
52	12.1. My family and relatives	Self-determination, interpersonal relations
53	12.2. My friendships	Self-determination, interpersonal relations
54	12.3. My colleagues	Self-determination, interpersonal relations
55	12.4. The circles	Self-determination, interpersonal relations
13	**Choosing appropriate life goals and choosing activities important to me**	
56	13.1. What does life goal mean	Self-determination, social inclusion
57	13.2. It starts happening	Self-determination, social inclusion
58	13.3. The plan is ready	Self-determination, social inclusion
59	13.4. My life goal worksheet	Self-determination, social inclusion
14	**Choosing end life care and palliative care**	
60	14.1. What are the end-life and palliative care.	Self-determination, physical &existential well-being
61	14.2. The patient as an active party in the palliative care	Self-determination, physical & existential well-being
62	14.3. Choosing end-life and palliative care	Self-determination, physical & existential well-being
63	14.4. First steps to choose palliative care	Self-determination, physical & existential well-being
64	14.5. The sequence in choice making for palliative care	Self-determination, physical & existential well-being

All the educational materials for increasing the skills and knowledge of AAWID and to assist in the implementation of the strategies and the practical exercises are accessible through the MNAM platform.

The platform has the following specific objectives:

- Provide tools and materials to train on the importance of developing and maintaining the factors of wellbeing, social participation and Independence as elements of Quality of Life for people with intellectual disabilities.
- Ease the navigation through the educational materials and practical exercises developed in TRIADE2.0 project.

- Homogenize the practical resources and advises for implementing the exercises with textual and visual information.

The system is intended to be available online 24 hours per day, 365 days per year with the exception of scheduled and pre-notified system maintenance downtimes, if needed. The system is non-critical. Temporary inaccessibility, even up to several days, will not create a substantial burden on any user. The host site for the system will be configured so as to include data backup capabilities and protocols. ITACA will maintain a copy of the code on UPV network, which has daily backup protocols.

1. The key of the learning process: 64 exercises.

The MNAM interactive platform has been designed as a tool to help professionals -educators- to improve the social inclusion and/or Quality of Life of ageing adults with intellectual disabilities (AAWID). The MNAM Platform provides 64 learning exercises, in different formats, which are the core of the learning process. The 64 exercises are grouped within 14 didactic units. The didactic units are clustered around the 3 factors of Quality of Life: well-being, social participation and independence.

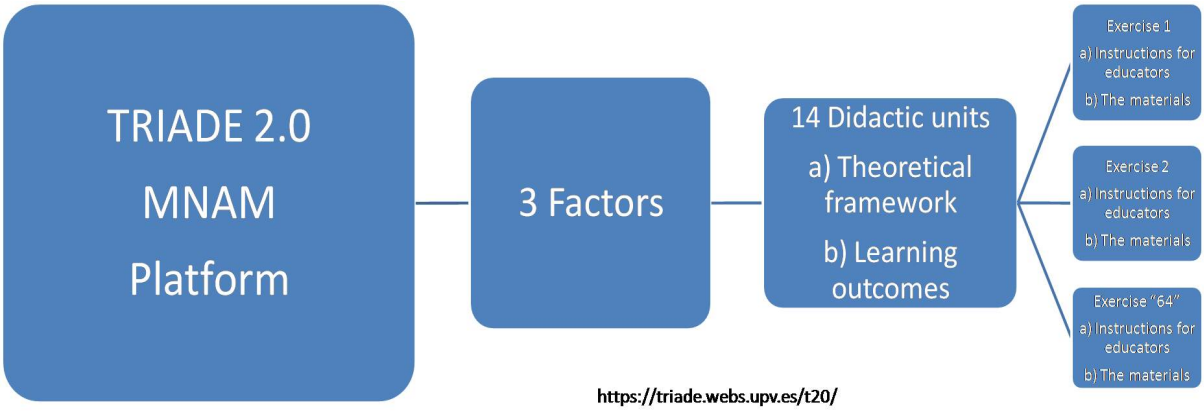

Figure 4-17: TRIADE 2.0 MNAM Platform pedagogical structure.

From the pedagogical point of view, each exercise comes with its pedagogical instructions. In addition, there is a unit introduction providing a theoretical framework for the exercises and indicating the learning outcomes to be achieved with the exercises. This theoretical foundations have been developed, as much as possible, using the theoretical contents of the units 1, 2 and 3 of this workbook.

These three pedagogical elements -theoretical framework, instructions and learning outcomes- are aimed at giving to educators general orientations of how an exercise might be carried out. But it should be highlighted that the platform has been designed to give freedom to educators and professionals to use -or adapt- each exercise and platform theoretical content to the specific support needs and contexts of AAWID.

The exercises have not been designed to be used directly by AAWID, without any help from the professionals. An educator should be always present in the learning activity, guiding the whole learning process and activities linked to the exercise.

Therefore, professionals/educators can freely use the exercises in the best way that matches their clients' needs. They might use one exercise -or a set of them- independently, adapt it for a given person or group, to implement it individually or by groups, to use it a part of other clients individual support methodologies.

In addition and related to the learning outcomes (knowledge and skills), it should be highlighted that both refer and are based, as much as it has been possible, on the contents of the unit 3 of this workbook (Table listing the support needs" and "support activities and strategies").

Class activity "1".
(20 minutes)
Find the exercise 1 of unit 2 (Difficulties in the activities of the daily living) on the platform, download the exercise, read the instructions, and discuss with a classmate or by groups the following issues:

1. The learning outcomes of this exercise are relevant and reachable by my target group?
2. Can you tell if the learning outcomes are based on the workbook?
3. Are the exercise instructions clear to you?
4. Would you work it with a single person or by groups?
5. Could you -or your group- suggest didactical tips or adaptations to carry out this activity with your target group?

2. Getting familiar with the platform and bringing the 64 exercises into play.

These are the steps suggested to educators to use the platform and carry out a lesson:

1st: getting familiar with the pedagogical approach of the platform and the 64 exercises

Disability professionals in charge of using the platform are recommended to get familiar with the whole platform and, specifically with the 64 exercises, trying to figure out how each of the 64 exercises -or a whole didactic unit- might fit within the organization support activities, the support needs or/and the Person-Centred Planning or their clients.

2nd: Searching for a given exercise

Educators and professionals might decide to use all the exercises included in the platform, giving the lessons with the same sequence in which they are numbered in the platform, or they might want to use one or all the exercises belonging to a given unit. To do so, they can use the landing page where appear the section "exercises" or "units" and download the exercise.

But, the MNAM platform also allows educators to find an exercise by searching by four key criteria: Quality of Life dimension, type of learning (individually or by group), estimated length and format of exercises (pdf, video, etc.).

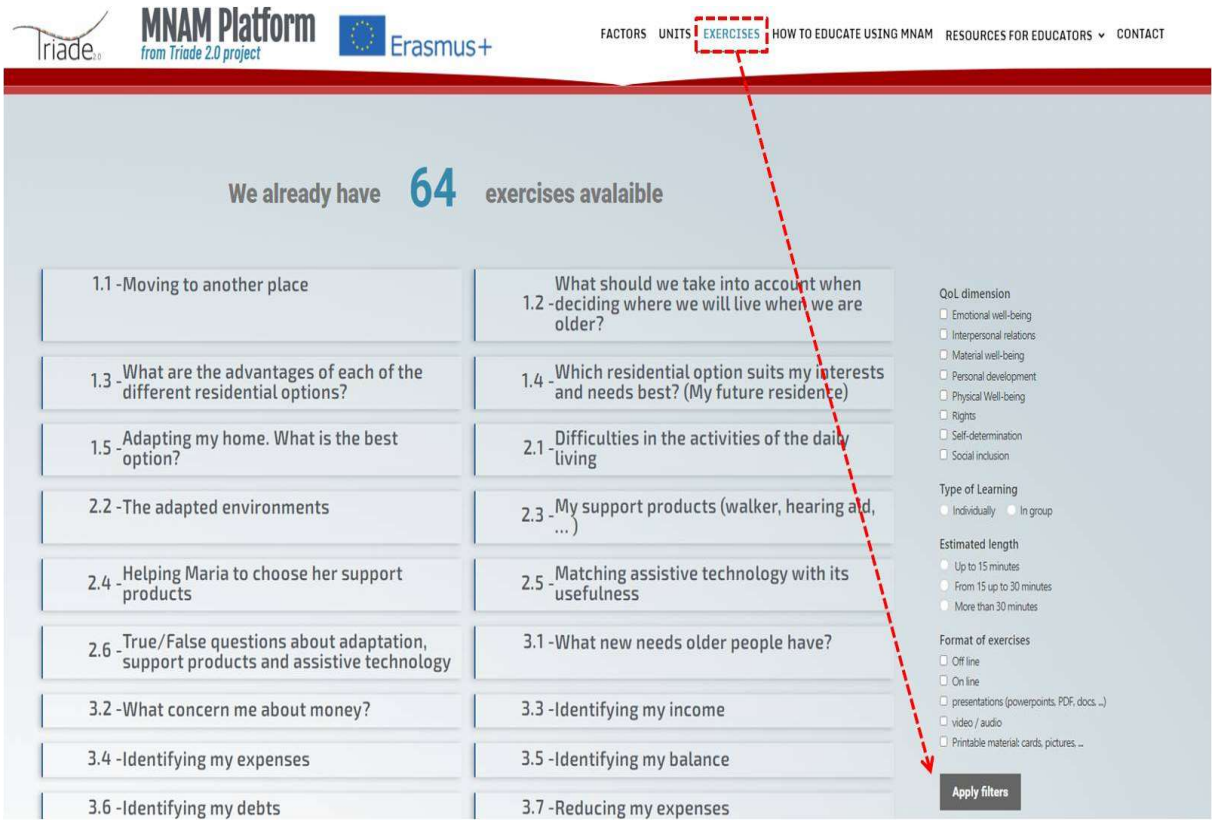

Figure 4-18: Searching exercises by 4 criteria.

Class activity "2"
(5 minutes)
By using the tool "search", could you find the exercises:

a) Working the social inclusion dimension?
b) To be implemented individually?
c) with a estimation length from 15 up to 30 minutes?

3rd: Using the platform resources to prepare the lesson

Once the educator has chosen an exercise -or a set- to carry out a learning activity, it might be very useful to read the pedagogical instructions and learning outcomes before starting the lesson. In case the educator needs further theoretical information about the exercise, can read the information given in the section "unit introduction" in which this exercise is included.

4th: giving the lesson

As it was stated before, professionals are free to use or adapt the exercise to the real support needs of the person -or group- and their context.

Professionals should take into account that the platform does not include any tool or methodology to evaluate if AAWID are reaching the learning outcomes. In case the professionals wish to evaluate and record the learning progress of the AAWID, it should be used own-made or external tools.

Table 4-2: Summary of steps to be carried out by the educator

Step	Remarks
Getting familiar with the platform.	Remember: exercises and units have been obtained from this workbook. How to use the platform in my daily work with my clients.
Searching an exercise.	Several ways to find an exercise: - going to exercise section in the landing page. - Going to unit section in the landing page. - Using the search criteria.
Using the platform resources to prepare the lesson.	Educators to read: 1. The theoretical explanation of each didactic unit. 2. The learning outcomes of each didactic unit. 3. The pedagogical instructions of each exercise.
Giving the lessons.	Download the exercise and print it if necessary. Freedom to use and adapt each exercise to the needs of our clients and their context. No evaluation of learning outcomes achievement included.

References Unit 4

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