

**Family education "MeTURA-Back to the Roots", therapeutic family gardening and therapeutic family cooking to support the independent life of adult family members with learning disabilities**



## **SUMMARY OF THE SYNTHESIS REPORT**

**Activity O1, A study of the opportunities for lifelong learning for adults with learning disabilities and their families and the possibilities to continuing that lifelong learning at home in a family setting.**

Gathered by Education Centre Geoss (Slovenia) together with Zveza Sožitje (Slovenia), Danilo Dolci (Italy), UOSIKAZU (Croatia) and Thrive (United Kingdom)

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## 1 INTRODUCTION

“MeTURA - Back to the Roots” is a project delivered as part of the Erasmus+ program, Key Action 2 (KA2). It aims to improve lives of adults with learning disabilities by encouraging therapeutic family gardening and cooking as a way of supporting the ongoing lifelong learning (LL) and independence of adult family members with intellectual (learning) disabilities (AFMID). Therapeutic gardening and cooking relates to gardening or cooking activities which focus on improving the general health, wellbeing and social integration of individuals (for example, by learning to grow and cook nutritious food or to take part in everyday activities that can be shared with other members of the family). Lifelong learning refers to all purposeful learning activities undertaken on an ongoing basis throughout a person's life, which aim to improve the individual's knowledge, skills and competencies.

The project will last for 35 months and is a collaboration between non-profit organizations from Slovenia, UK, Croatia and Italy. The participating organizations are: Education Centre Geoss (Slovenia), Zveza Sožitje (Slovenia), Danilo Dolci (Italy), UOSIKAZU (Croatia) and Thrive (United Kingdom). The end result of the MeTURA project will enable partner organizations to expand the lifelong learning opportunities available to vulnerable adult learners. The project aims to develop toolkits and resources to enable educators and families to make the most of the lifelong learning opportunities that therapeutic gardening and therapeutic cooking can provide. It will provide insights into how new competences and skills are acquired and the best approaches and resources for supporting the acquisition of these, as well as into the therapeutic benefits of these activities.

Initial investigations by project partners suggested that the majority of adults with learning disabilities live at home with their families and that each family would benefit from a personalized approach to lifelong learning, adapted to their own needs and circumstance. The aim of the first phase of the study (O1) was to explore the current opportunities for lifelong learning for families and AFMID at home and in their local area. Information gathered will be used to guide the development of new resource and tools for self-directed learning (andragogic tools). These tools will provide educators and activity providers with a method for supporting family gardening and cooking at home as a way of encouraging learning and independence for adult family members with intellectual disabilities.

As part of the O1 study, a questionnaire was distributed to families with AFMID in each participating countries. We wanted to find out firstly, if the families and

AFMID attend any educational or other activities and, if so, which ones and secondly what are their reasons for not attending particular activities (e.g. difficulties and barriers they face). In particular, we were interested to discover if families were interested in attending activities together with their AFMID and, if so, whether they would be interested in taking part in therapeutic gardening and cooking together and what benefits they believed they might gain from these activities.

The questionnaire was divided into three sections; the first part consisted of some general questions about the family, the second part consisted of 12 closed questions (multiple choice) that were answered by whole family, while the third part consisted of one open and 3 closed questions and was written in an easy read format for those AFMID unable engage with the questions in the previous section.

In this report we present a short summary of the formal education and life-long learning opportunities for people with learning disabilities in each partner countries, along with the questionnaire results.

## 2 SUMMARY OF THE NATIONAL REPORT FOR SLOVENIA

### 2.1 SCHOOLING AND TRAINING FOR ADULTS WITH LEARNING DISABILITIES

Special education programs for people with learning disabilities in Slovenia divide into:

- **An obligatory part**, lasting 9 years and with 3 stages: first (I), second (II), and third (III). Each stage involves 3 years of schooling, and it lasts until the person is 18. This obligatory part may be followed by an optional fourth (IV) stage of schooling, lasting 3 years.
- **A follow up program** (optional) is available from the age 18. – 26. This lasts eight years, and is called “**Learning for life and work**” and involves a fifth (V) stage (3 years) and sixth (VI) stage (5 years) (Republic of Slovenia, Ministry of education, science and sport, 2014).

Students finish obligatory schooling after they have attended the I, II and III stages, for three years on each stage. When they finish their education on other levels of educational program, they get a certificate with description of the achieved goals and recommendations for their further development. When they finish program “Learning for life and work”, they are given a certificate with their estimated level of achieved development, a description of their knowledge, and suggestions for their successful inclusion in life and work.

In the MeTura project, we are concentrating on adults with learning disabilities. Adults with learning disabilities are individuals who have a significant limitation of both intellectual capability and adapted behavior, which is reflected in their conceptual, social and practical adaptation skills.

Education for adults with learning disabilities in Slovenia still needs to be improved. Often their wishes, needs and interest in further education are neglected. Like all individuals, adults with learning disabilities differ in their capabilities which is why they require an individual approach that takes into account the needs and capabilities of each individual.

### 2.2 LIFELONG LEARNING FOR PERSONS WITH INTELLECTUAL DISABILITIES

In Slovenia, the responsibility for lifelong learning for persons with learning disabilities is included in the category of social affairs. Article 17. of the Social Assistance Act states that “all-inclusive care of adults who are physically and intellectually disabled, their development, individuality and harmonic inclusion in

the community and environment, keeping their gained knowledge and developing new capabilities" is part of the social security services (Social Assistance Act, Article 17.). This means that the need for further education or lifelong learning of these persons is the responsibility of the institutions that offer social security services. Also, Article 10. of the Social Inclusion of Disabled Persons Act states that, in order to ensure the social inclusion of people with disabilities in the community, individuals with disabilities have the right to services provided by social inclusion services in the community to support equal coexistence of people with disabilities and non-disabled persons in the community. Article 10. specifically mentions Lifelong learning as a service of Social Inclusion.

Lifelong learning for individuals with learning disabilities in Slovenia is mainly provided within Occupational Activity Centers. The other main providers of life long education in Slovenia for individuals with learning disabilities are NGOs. The most widely known is the Slovenian association for persons with learning disabilities (Zveza Sožitje), a partner in this project and which connects 51 local societies (Društvo Sožitje) all over Slovenia as well as the Special Olympics Slovenia.

## **2.3 PROGRAMS OF LIFELONG LEARNING FOR INDIVIDUALS WITH LEARNING DISABILITIES OFFERED BY ZVEZA SOZITJE AND OCCUPATIONAL ACTIVITY CENTERS**

### **Zveza Sožitje activities**

Zveza Sožitje offers different programs of lifelong learning for individuals with learning disabilities. Training for independent, active life and work for individuals with learning disabilities includes learning on how to take care of him/herself, seminars for girls and boys, self-advocacy and experience camps. The program is designed to teach individuals with learning disabilities how to take care of themselves, how to take decisions on certain matters by themselves, how to be their own advocate and to become aware of their rights and duties as an adult. The goal of the program is to ensure that individuals with learning disabilities are equally included in everyday life and to recognize their right to make decisions that affect themselves and as well as the obligations that come from these rights (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Within the program Zveza Sožitje also offer computer training, camping – living in nature, experiential camps at the seaside, sport camps, art camps etc. They offer workshops, seminars or experiential camps where the participants gain new knowledge or strengthen their existing knowledge and skills. These skills and



knowledge are important to support their equal participation in everyday life and work. On experiential camps, participants gain skills in how to actively spend their free time, to take care of their physical needs and, because of the locations and special circumstances of the camps, the participants have to communicate with each other and jointly decide on activities.

Two other parts of the program are the “Abilimpiada Slovenia” and “MATP – Motor Activities Training Program”. Abilimpiada is an olympiad in skills, habits, working abilities and socialization. It is a competitive event that connects people with disabilities of all kinds, including people with learning disabilities. Competitors compete in categories of employment and leisure activities in which they show their creativity, knowledge and competences. MATP is a program for maintaining or developing motor skills in individuals with more serious learning disabilities.

Attending these programs helps people with learning disabilities to get to know their capabilities and raises their self-esteem and self-confidence. By attending seminars and workshops independently they prove themselves and others, that they are capable of more than the society is sometimes willing to admit (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Other lifelong learning opportunities offered by Zveza Sožitje include information provision and published materials. They publish various printed materials which inform users (individuals with learning disabilities and their parents), about the newest research relating to how to improve quality of life. There is often a lack of access to information for adults with learning disabilities since information has to be adapted to make it easily understandable for them. Because of this, they are less included in the educational processes, which is why the informative and publishing activities opportunities offered by Zveza Sožitje are an important aspect of lifelong learning for adults with learning disabilities (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Zveza Sožitje runs sporting activities for adults with learning disabilities through a NGO called Specialna olimpijada Slovenije (Special Olympics Slovenia). The aim of these activities is to support the psychophysical abilities and socialization of people with learning disabilities. The slogan of the Special Olympics is: "Let me win, but if I cannot win, let me be brave in my attempt."

Zveza Sožitje also encourages cultural activities which enable adults with learning disabilities to show their artworks and results of their year-round efforts in the field of culture. By presenting their own achievements and demonstrating their abilities at organized cultural events, adults with learning disabilities get affirmation and recognition for the quality of their own work and creativity.

At a national level, Zveza Sožitje offers training and education for families of adults with learning disabilities.

Programs of lifelong learning of local societies (Sožitje) are diverse. They depend on the availability of materials and space the capabilities of those involved and the availability of people to run activities; individuals that conduct activities in local societies are mostly volunteers. They offer programs such as computer workshops, workshops for strengthening reading and writing, English classes, dance schools, swimming classes, learning social skills, workshops for making products from different materials (craftwork), programs to encourage healthy lifestyle, first aid workshops, cooking workshops, excursions, activities to promote inclusion in the in the local community, etc. (Jordan Simončič, 2012; Zveza Sožitje n.d.).

### **Occupational Activity Center's activities**

Programs of lifelong learning that are conducted in an Occupational Activity Centers are written in their annual plans and they are developed based on the interest of individuals and their capabilities. Initial interviews with the adults with learning disabilities and their mentors are conducted to determine their wishes and capabilities, and based on this, an individual plan is prepared for them. which programs are run depends on the Occupational Activity Center. Some Occupational Activity Centers are more work orientated, they teach people with learning disabilities work processes and skills, teach them practical vocational skills such as making products by sawing, and carton gluing etc. Centers are increasingly aware of the importance of lifelong learning for people with learning disabilities and they pay attention to these aspects as well. They work on developing the individuals social skills, educate them for self-advocacy, teach them how to actively spend their free time, teach them computer skills, foreign languages, how to get involved in the community, they discuss subjects such as relationships, love, have cooking workshops, dance classes, reading classes, etc. (Jordan Simončič, 2012).



Since the population is aging, the Occupational Activity Centers are full and there are waiting lists for the people with learning disabilities who wish to be included. The government did not respond in time to this demographical change and Slovenia is currently facing a problem whereby those with learning disabilities have to stay at home after they finish their schooling until an open spots comes up in an Occupational Activity Center. This means that they are excluded from the lifelong learning and educational process. Lifelong learning processes in their home environment represents a good solution to ensure that people with learning disabilities do not stop with their learning process.

## 2.4 QUESTIONNAIRE ANALYSIS

25 families with adult family members with learning disabilities (AFMID) filled out the questionnaire. The age of AFMID that participated in the questionnaire ranged from 16 to 60 and the average age was approximately 32 years. The age of the parents ranged from 36 to 78 and their average age was approximately 55 years.

According to the results, majority of AFMID that participated in the questionnaire live at home (96 %) and the majority attend an Occupational Activity Center or activity group (64 %). Most families and AFMID have opportunities to attend activities close to their home (84 %). These are mostly sport activities and various (weekend) workshops. The most frequently stated reason why the families do not attend activities was the distance from home (8 families stated that), followed by health reasons (8 families).

Most of the families and AFMID would be interested in gardening and cooking activities (approx. 60 %) but the majority of the parents would not attend the workshops with their AFMID (only 44 % o would attend the workshop).

When we asked AFMID about their favorite meal, the answers were simple dishes and in half of the cases the AFMID does not know how to prepare it but would like to learn to prepare it and to grow the ingredients by themselves, to gain new skills, greater independence and because these activities provide better well-being.

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### 3 SUMMARY OF THE NATIONAL REPORT FOR ITALY

In this national report for Italy, formal educational opportunities for adults with learning disabilities are first presented, followed by their options after finishing formal education and the offer of lifelong learning available to them. Finally, the questionnaire results for Italy are presented. The questionnaire was conducted among families that have Adult Family Members with Intellectual Disabilities (AFMID).

#### 3.1 SCHOOLING AND TRAINING FOR ADULTS WITH LEARNING DISABILITIES IN ITALY

In Italy, education and training are a right, but also a duty. The State guarantees everybody the right to education and training up to the age of 18, for 12 years from the beginning of the first class of the Primary School.

The children who have a certified disability also have the right, to enroll in a nursery. Moreover, children who are certified at risk (in accordance with paragraph 3d of art. 3d Law No. 104 of 1992) have the right to priority access to the public services in the municipality of residence.

#### 3.2 SCHOOLING FOR INCLUSION

In Italy all pupils with disabilities attend common schools. In fact, since 1977 almost all “special” schools (attended only by pupils with disabilities) have been closed. To enable the inclusion of pupils with disabilities, the school must guarantee specific and additional resources, based on the needs of each student:

1. a specialized support teacher;
2. an autonomy and communication assistant;
3. a basic assistant (to deal with personal hygiene taking into account the gender of the student, and to support transfers within the school).

Students with disabilities can also:

1. have more time to do tests or do them in different ways to their companions;
2. follow personalized programs, which may be different from those of the companions;

3. take different tests from those of the companions: equivalent tests or differentiated tests.

### 3.3 LIFELONG LEARNING FOR PERSONS WITH LEARNING DISABILITIES

With regard to the possibility of orientation and professional training for people with learning disabilities, the Italian situation is complex, differentiated and often unsatisfactory. Ideally, after middle school, adolescents with learning disabilities should have the opportunity to attend professional schools with staff resources and with adequate teachers to promote the integration of people with learning disabilities. Often this does not happen and they are enrolled in other schools (including scientific or classical high schools).

This choice is due to several factors, but the main one is the fact that, in many regional situations, professional courses are scarce and / or badly organized and / or with staff that are not very sensitive to the problems of integration. It should be emphasized even if there are some very well organized and avant-garde opportunities: they are in the minority.

Taking note of this widespread lack, it must however be emphasized that since the years around 1970 Italy has promoted experiences of orientation, professional qualification and cutting-edge work placement.

The right to professional training of disabled citizens is enshrined in art. 38 of the Italian Constitution: "the disabled and the handicapped have the right to education and professional training".

Until the sixties, however, the regulations did not provide for interventions in favor of people with disabilities. With the L. n. 118/71 the first indications of such provision were given and, then, with the L. n. 845/78, more specific provisions in this regard were introduced such as ensuring coherence between the vocational training system and the general education system, the professional qualification of the disabled, interventions to ensure them the right to vocational training, direct training initiatives for the professional re-education of workers who have become disabled and the identification of individuals who are not fit to attend normal courses. L. n. 104/92 lead to the integration of what had already been provided.

It ensures that the Regions guarantee disabled students who are not able to use ordinary learning methods the opportunity to acquire a qualification and also the provision of specific activities within the range of activities provided by the vocational training centre, that take into account the individual requirements/needs that emerged from the educational plans developed during earlier schooling. To this end, the Regions provide the centres with the necessary subsidies and equipment. The courses take into account the different abilities and needs of the disabled person who, consequently, is included in common classes or in specific courses or in pre-training courses. However, there is little (only a few hours) or no support.

A very important law for people with disabilities in Italy was approved in 1992, the famous “104 Law”. The law, 5 February 1992 n. 104, better known as law 104/92, is the legislative regulation "for assistance, social integration and the rights of disabled people".

The main recipients of Law 104 are therefore the disabled, but there are also references to those who live with them. It suggests that autonomy and social integration are achieved by guaranteeing adequate support to the disabled person and the family. And this support can be in the form of personal or family help services, but can also be understood as psychological, psycho-pedagogical and technical help.

After its instigation, Law 104 was updated in some parts, as a result of rules introduced later. Article 12 of Law 104 guarantees the right to education for disabled people in nursery schools, in the common classes of educational institutions of all levels and in university institutions. Learning difficulties or other difficulties deriving from disabilities should not prevent the individual from access to education.

Article 17, on the other hand, concerns PROFESSIONAL TRAINING and according to this article, it is the Regions that have the responsibility to implement the inclusion of the disabled person in ordinary courses of professional training at public and private centres. They must also guarantee disabled students who are not able to use the ordinary learning approaches the opportunity to acquire a qualification through specific activities provided by the vocational training centre. Taking into account the individual requirements that emerged from the educational plans, developed during the scholastic process.



These vocational training courses must take into account the different abilities and needs of the disabled person who is included in common classes or in special courses or in pre-training courses.

### 3.4 GOOD PRACTICES

#### **Training and job opportunities for people with disabilities in 16 Italian regions**

Launch of a new project open to young people with disabilities aged between 18 and 40 who are interested in entering the labour market

It is estimated that in Italy there are about 4 million 360 thousand people with a disability, or 7.2% of the population. According to the National Health Observatory in the Italian regions, the percentage of disabled people aged 45 to 64 employed is 18% (against 58.7% of the general population for the same age group) with significant gender differences. In fact, 23% of men with disabilities are employed (against 71.2% of men in the rest of the country) and only 14% of women (against 46.7%).

Italy is pleased to report an important new opportunity for those who are disabled and looking for work: the new scheme was launched by the UILDM - Italian Union for the Fight against Muscular Dystrophy. This is the 'PLUS' project, the socio-occupational inclusion initiative for people with disabilities, which won the first "single" call for proposals envisaged by the reform of the Third Sector. Issued in November 2016 and financed by the Ministry of Labour and Social Policies, that gave jobs to 80 young people with disabilities (5 for each of the 16 participating regions).

The project carried out together with the Movimento Difesa del Cittadino partner, Anas Puglia - National Association of Social Action and the Atlantis Association 27, consisted of the activation of job training grants, which lasted 18 months and took place in 16 regions. Involving at least 5 people with disabilities from 18 to 40 years (5 for each region). 11 of the 16 participating regions were reserved for women.

It included two main activities: in the first the participants followed a 40-hour professional training course through which they were offered the necessary tools to promote personal and social autonomy and acquire an adequate working and relational capacity. Later they were supported in work placement in companies, cooperatives or public bodies through 30-hour training periods, in

order to put into practice what they have learned in the classroom and be able to have a first opportunity in the world of work. For each beneficiary, the degree of ability, autonomy and personal aptitude was noted, in order to create a CV identifying the most appropriate location and type of internship.

The second activity involved the creation of a reception and listening desk, independently managed by people with disabilities, with the aim of providing advice and assistance in entering the world of work. This second activity was attended by 32 people selected from the 80 initial recipients.

### 3.5 QUESTIONNAIRE SUMMARY

The questionnaire was filled out by 22 families with AFMID. the age of AFMID that participated in the questionnaire was between 18 and 81, their average age is approximately 49,5 years. The age of parent 1 was between 52 and 92, their average age is approximately 64 years, the age of the second parent was between 54 and 88, their average age is approximately 64,5 year.

According to the results, half of the AFMID that participated in the questionnaires live at home (46 %) and the majority visit a day centre or activity group (64 %). The majority of the families and AFMID have opportunities to attend activities together (57 %), mostly sport activities, excursions and cooking workshops. The most frequently stated reason why the families do not attend activities relates to the lack of opportunities on offer (12 families stated this), followed by the price of the activities. This suggests that it is beneficial to widen the scope of activities, to provide better opportunities for the families to attend lifelong educational processes.

Almost all the families and AFMID (91 %) would be interested in gardening and cooking activities and the majority of the parents would attend the workshops with their AFMID (73 %).

When we asked AFMID about their favourite meal, the answers were sophisticated dishes and in most of the cases the AFMID knew how to prepare them. They did wish to grow the ingredients by themselves, to gain new skills, greater independence, because these activities provide better well-being.



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## 4 SUMMARY OF THE NATIONAL REPORT FOR CROATIA

In Croatia, adult education is highlighted as an important component of the education system, and its confirmation comes from a number of important strategic documents. Today, the activities of adult education are taking place at the Agency for Vocational Education and Adult Education established by the Agency for Vocational Education and Adult Education Act. In Croatia, adult education includes all forms of education of individuals over the age of 15. The law stipulates that adult education is based on the principles of lifelong learning; the rational use of educational opportunities, territorial proximity and the availability of education to all under equal conditions, in accordance with their abilities; freedom and autonomy in choosing the content, forms, resources and methods; appreciation of diversity and inclusion; professional and moral responsibilities of andragogical staff; guaranteeing the quality of educational offerings and respecting the personality and dignity of each participant.

There are over 500 different institutions in Croatia that run adult education programs. Very few of these institutions implement programs through which it is possible to acquire knowledge and skills in a very narrow and specific field of work. In the last 10 years, the rights to live in a community and the decrease in social exclusion of those with disabilities and the promotion of social innovations and their inclusion in society, as set out in the Europe 2020 Strategy, the United Nations Convention on the Rights of Persons with Disabilities and many other legal documents have been more intensively discussed and because of that a need to develop adult education programs in the area of community social services for people with learning and mental disabilities has emerged. The area of lifelong learning for those with disabilities in Croatia includes the distinction between formal, non-formal and informal education, with a clear definition of the way of recognizing knowledge obtained informally.

- *Formal education refers to the inclusion of people with learning disabilities into regular education through the use of inclusive practices and is based on human rights.*

The main form of education for students with learning disabilities were special educational institutions which are special schools or special departments in



which specialists educated children with learning disabilities separated from other children. Separation of children from families and accommodation in special institutions has proved to be useless because the methods were often inappropriate and below the level of capabilities of those children. Because of this, the potentials needed for successful integration, were not fulfilled. Strong support for the integration of children with learning disabilities into the regular educational system was provided by the ideas of equal education and education for all, regardless of the existing differences, based on the 1948 Human Rights Declaration. Also by a number of other international and national documents that were later adopted, and among them the utmost importance has the UN Convention on the Rights of Persons with Disabilities. Based on the Convention, the National Strategy for equal opportunities for individuals with disabilities from 2017 to 2020 was adopted. Its goal is to progress and enhance the protection of the rights of people with disabilities in order to make the Croatian society as sensitive and adapted to the necessary changes in favor of equalizing the opportunities of individuals with disabilities. For whom it is necessary to create the conditions for their active inclusion and equal participation in society, respect the innate dignity and respect the special interests and prevent any form of discrimination. More recently, the term educational inclusion or inclusion of everyone in education is more frequently used. The main objective of the educational inclusion is not only to integrate children into a system of regular education but also to provide a series of conditions that create an ongoing process in which the educational and living needs of children with special educational needs, including children with learning disabilities, will be met.

According to the latest available data from the Croatian National Institute of Public Health in the Republic of Croatia, there are 511850 individuals with disabilities, out of which 307934 are men (60%) and 203916 are women (40%). This means individuals with disabilities make up about 11.9% of the total population of the Republic of Croatia. Of the above, the number of individuals with disabilities 4,8% are people with learning disabilities, and 29,6% of individuals with disabilities have multiple disabilities that contribute to the functional impairment of the person with the disability. Of individuals with disabilities, according to the available data of the social welfare system in the majority (80%) live in the family while about 17% of them live on their own. About 0.5% have a foster parent or a

guardian, and 0.57% of people with disabilities reside in an institution. Learning disability with a 66% share of mild learning disability is the most common specified cause that determines the need for an appropriate form of education. The most common form of specialized implementation of complete educational integration is through teaching methods with individualized access and special additional help (defectologist, speech therapist, psychotherapist, etc.).

- *Non-formal education of individuals with learning disabilities are the result of everyday activities in the work environment, in the family or in the free time and usually do not end with the issuance of an official document.*

Throughout history individuals with learning disabilities were mostly degraded and disadvantaged, often labeled as undesirable and it was thought that as such should be separated from society. Because of that they were mostly treated through some form of segregation system. During the sixties of the last century there was a significant change in attitude towards disability and its interpretation. The medical model of disability has gradually changed into a social model and the goal of its policy towards individuals with learning disabilities is no longer that of therapy and protection, but the full inclusion of people with learning disabilities in society, while exercising all their rights. Under the influence of the mentioned processes, emerges the policy of deinstitutionalization of individuals with learning disabilities in the context of the realization of the right to a life in the community. In the last century, in order to enable people with learning disabilities to fully participate in society and to exercise the right to live in a community, many developed countries of the world have been actively pursuing the deinstitutionalization policy with the development of adequate community support services. Progress has been made in Croatia, especially through the process of inclusion that started in 1997. Community service centers, community-based housing support for people with intellectual disabilities and civil society organizations are increasingly establishing support services made up of experts such as defectologists - rehabilitators, social workers, psychologists, doctors / nurses and other professionals, which are necessary for lifelong learning to acquire skills for everyday life in the community. However, these support services and projects promoting inclusion in lifelong learning are most often carried out in the premises of those services that organize the activities. That is why families and AFMID who are not involved in

such services are unsupported in finding ways to learn skills of everyday life. This is a problem and it is demanding for families who have AFMID with combined (intellectual and physical) disabilities and live in rural and poorly developed and poor areas because they must invest more financial resources and separate more time. Through years of working experience of UOSIKAZU, we have noted that there are unused potentials for lifelong learning at home and in the familiar environment of AFMID, where additional skills and supportive andragogical methods can provide quality lifelong learning at home with the assumption that it will enable greater social inclusion rather than isolation of the family. Inclusion of AFMID in everyday family activities gives a person a sense of personal value, allows her/him to express, develop her/his talents, independence and autonomy and establish common interests with other people.

- *Informal education implies various forms of acquiring knowledge and skills that involve self-initiated or spontaneous forms of learning that take place in everyday life.*

Such types of learning can greatly help AFMID. The largest source of information here is the internet on which there are numerous e-platforms, web portals with interesting learning contents and social networks among which some are suitable for easy and simple searches. Informal situations offer a range of opportunities for acquiring knowledge. For this reason, informal learning could be an important innovation in learning and teaching methods in the future. Establishing a system of lifelong learning for families and their adult members with learning disabilities in the concept of bringing lifelong learning closer to their home ultimately depends on their interests and realistic opportunities for implementing the family lifelong learning as well as on how recognized and supported that would be by the community service providers. That is why the study carried out through the MeTURA project is so important, and the analysis of this study will surely provide valuable guidance for the implementation of lifelong learning for AFMID in their home. For families and AFMID lifelong learning is not just acquiring new skills and knowledge but also integrating in society which means that they can represent themselves and take more control over their daily lives.

#### 4.1 QUESTIONNAIRE ANALYSIS

According to the results, almost all AFMID that participated in the questionnaires live at home (95 %). The majority visit a day center or activity group (55 %). The majority of the families and AFMID do not have opportunities to attend activities close to their home (85 %). The most frequently stated reason why the families do not attend activities was, the distance from home (11 families stated that). Most of the families and AFMID would be interested in cooking (65 %), as less than half the families would be interested in gardening (40 %). The majority of the parents would not attend the workshops with their AFMID (70 %). The most frequently stated reason to attend activities was acquiring new knowledge and skills. Most of them would like to learn about cooking and gardening through workshops and lessons guided by an experienced trainer (11 families stated that).

When we asked AFMID about their favourite meal, the answers were simple dishes and in most of the cases the AFMID did not know how to prepare it, but would wish to learn, to gain greater independence.

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## 5. SUMMARY OF THE NATIONAL REPORT FOR UNITED KINGDOM

### 5.1 TERMINOLOGY

In the UK, the term “learning disabilities” is still widely used although the term “intellectual disabilities” is gradually becoming more common (in part to prevent confusion with the US where “learning disabilities” is used to describe individuals with what would be termed in the UK “learning difficulties” e.g. dyslexia.) This report will use the term “learning disabilities”

### 5.2 CURRENT STATE IN THE UK

Around 1.5 million people in the UK have a learning disability which includes over 1,100,000 adults<sup>2</sup> (about 2.16% of adults in the UK and 862,995 adults of working age). About 350,000 people have a severe learning disability These figures are increasing, primarily due to reductions in mortality<sup>1</sup>. The majority of individuals with learning disabilities (about 78%) have no support from specialist living disability services, only about 22% are known to learning disability services<sup>6</sup>. Half of all adults with a learning disability live in the family home, others live in supported living or residential care and a smaller number live independently<sup>6</sup>. Overall about 77% are living in the community in one form or another and the UK government is committed to further reducing the numbers in inpatient care by 2027. Only 1 in 3 people with a learning disability take part in some form of education or training<sup>2</sup> and in 2014/15 only a small number 7,500 were in paid employment and the majority of these were working less than 16 hours per day<sup>6</sup>. People with learning disabilities have more health care needs than the general population (about 50% will have at least 1 significant health problem). They are also much more likely to have issues around diet and exercise; less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet with an insufficient intake of fruit and vegetables and are less likely to engage in physical activity<sup>6</sup>.

### 5.3 SUPPORT IN UK

In recent years there has been an increasing drive in the UK to provide opportunities for independent living and working environments within the local community for adults with learning disabilities and in particular to move adults with learning disabilities from hospitals to their own homes in the community<sup>10</sup>. There has also been a focus on reducing discrimination and providing

opportunities for paid employment. Provision for individuals with disabilities has become more specialized, with separation of disability support into specific disability groups. Groups such as those with Autistic Spectrum Disorders and Asperger's syndrome are now becoming recognized as distinct disability groups (since, for example, not everyone with autism will have a learning disability<sup>6</sup>). More adults with learning disabilities are now living with families which has led to greater strain on carers (7 out of 10 families caring for someone with profound and multiple learning disabilities report having reached or come close to breaking point because of a lack of short break services<sup>6</sup>.) Over 50% of family carers report that they spend 100 or more hours a week caring for the person with learning difficulties and about 75% have been caring for the individual for more than 20 years<sup>5</sup>.

#### **5.4 FUTURE FOCUS – PROMOTING INDEPENDENT LIVING AND SOCIAL INTEGRATION**

A report by Lancaster University in 2008 looked at the predicted changes in the needs of adults with learning disabilities in England for social care services from 2009 to 2026.<sup>4</sup> They predict that there will be a significant increase in the number of older people with LD and in young adults with complex needs and learning disabilities.

#### **5.5 EDUCATIONAL OPPORTUNITIES FOR ADULT FAMILY MEMBERS WITH INTELLECTUAL DISABILITIES (AFMID) IN THE UK**

Gardening and social and therapeutic horticulture are common activities that AFMID take part in, providing social, vocational and therapeutic benefits., A survey in 2017 by the Green Care Coalition investigated the provision of gardening for health & wellbeing in the UK<sup>8</sup>. Learning disabilities was one of the most common groups that organizations were working with (53%), secondly only to mental health.

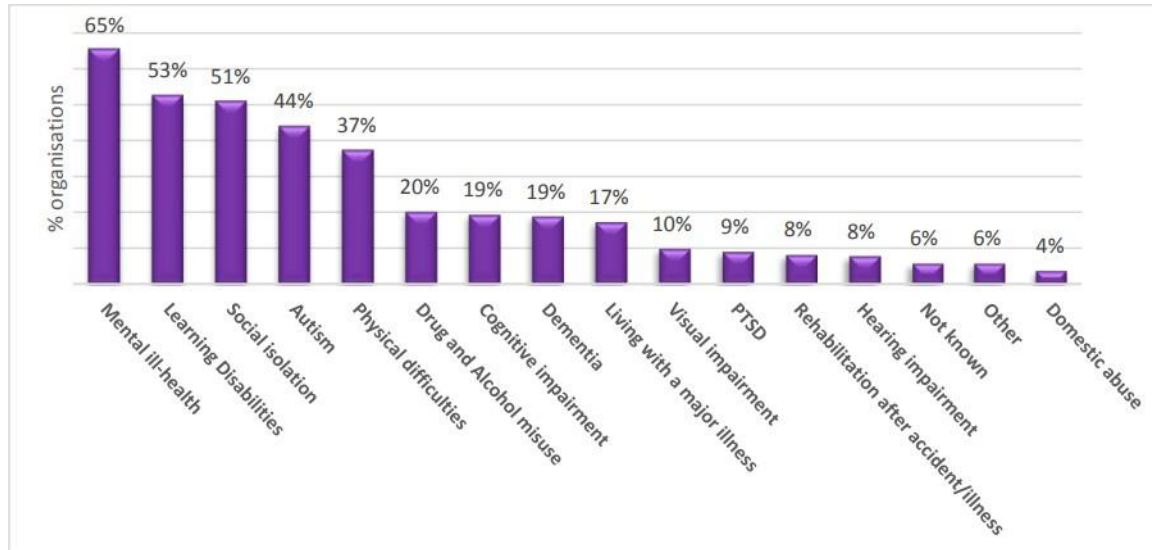


Figure 1: Categories of service-users accessing services

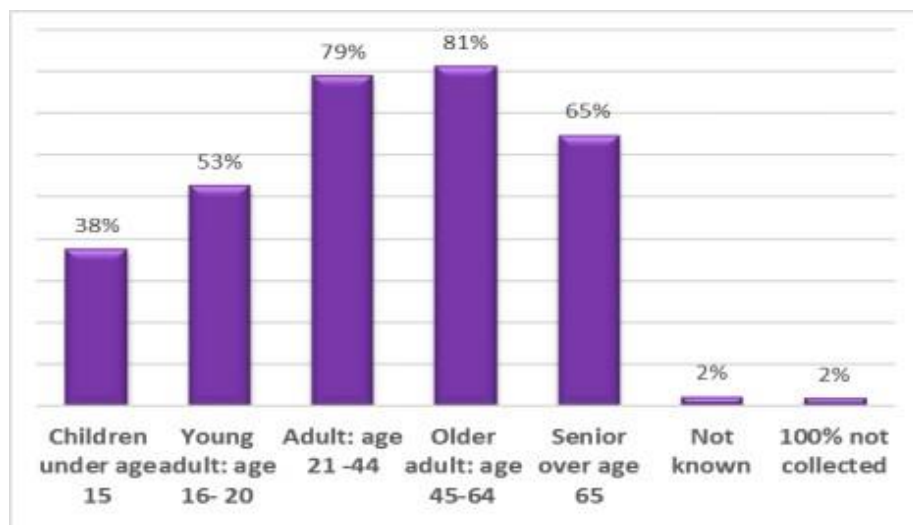


Figure 2: % Organisations with participants in each age category

The majority of organizations are working with adults (over the age of 21) although just over a half are working with young adults 16-21 yrs. 84% of organization work with mixed age group adults.

Similarly, a 2017 survey of UK care farms<sup>9</sup> (many of which provide gardening alongside farming) found that 93% of care farms in the UK were working with people with learning difficulties and 86% with individuals with autism spectrum

disorders. Many participants have more than one issue/disability and most gardening sessions are run with mixed disability groups for individuals rather than families.

Some young adults with a learning disability may remain in education or training, free of charge, until they are 25 if it is agreed that it would be beneficial for them to do so. (for example, those in England who have an Education, Health and Care (EHC) Plan). Many Further education colleges in the UK have units working specifically with individuals with Learning Disabilities. These often provide courses or workshops in cookery and other life skills and some also provide gardening. But these are focused on individuals rather than family learning.

## 5.6 QUESTIONNAIRE SUMMARY

### Gathering the data

Minor modifications were made to the wording of the questionnaire to make the questions more understandable to a UK audience. An online version of the questionnaire was created in surveymonkey to allow the questionnaire to be shared more widely.

Thrive works with various individuals with learning disabilities through our gardening projects in Reading, Battersea and Birmingham to date we have not approached these groups as they all currently engage in gardening on a weekly basis and would be a very unrepresentative sample. We initially contacted three local educational colleges who have units working specifically to provide education for adults with learning disabilities and two charity organizations with provide support for individuals with learning disabilities. Since we have not had a response from these contacts we have been approaching other organizations. A request was also posted on our twitter feed (followed by 6,500+) this yielded 5 new charitable and community groups expressing interest and support. In total we have sent the questionnaire to 16 organizations who work with adults with learning disabilities.

## 5.7 QUESTIONNAIRE ANALYSIS

The results from the questionnaire suggest that the majority of AFMID are under 30 but living with elderly parents 50-65. Roughly 2/3 are living at home with the

remainder mainly living in a shared home or supported living. Only a small proportion are in formal schooling but 61% attend some kind of day center or activity group. Just over half of families have opportunities for activities near to them and the most common of these are family support groups, sports clubs and lectures on life skills. There are very few weekend workshops or family clubs.

The main barriers to attendance were lack of activities that the AFMID would like to attend in their local area and that the AFMID was not independent enough to attend alone. Distance was not mentioned as an explicit issue.

Over 80% of respondents were interested in cooking or gardening workshops and where interested in attending as a family along with the AFMID and there was a strong preference for workshops with experienced teachers or trainers.

When we asked the AFMID about their favourite meal many chose unhealthier, comfort or takeaway food such as, chicken korma fish and chips or pie and chips. Other clients were interested in simple dishes or some in more challenging cookery (the level of challenge possibly reflects the range of abilities of AFMID).

The majority cannot currently cook these themselves but many respondents commented that they can cook them “with help”. 67% were interested in cooking the dishes (possibly the others were not because their favourite meal was a takeaway dish) and they were interested

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## 6 CONCLUSION

Results of the questionnaire show similar situation in all participating countries; adult family members with intellectual disabilities (AFMID) are interested in participating in activities of lifelong learning and they would be interested in participating in cooking and gardening workshops as well. On the other hand, the majority of their family members did not express interest in joining their AFMID in these activities.

The reasons for AFMID not attending activities of lifelong learning was, in the majority cases, distance from home, so we can assume if the activities are organized in local or home environment of AFMID, they would be willing to participate. The challenge for further investigation is now how to motivate families and AFMID in participating in activities, which will be explored through next phases of the project “MeTURA – Back to the roots”.