

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



## SUMMARY OF SYNTHESIS REPORT

Activity IO3, Study of methods used by educators to motivate families and adult family members with learning (intellectual) disabilities (AFMID) to engage in lifelong learning (LL) in a social setting

Gathered by CSC Danilo Dolci (Italy) together with IC Geoss and Zveza Sozitje (Slovenia), UOSIKAZU (Croatia) and Thrive (United Kingdom)





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### **1 INTRODUCTION**

"MeTURA - Back to the Roots" is a project under the Erasmus+ program, Key Action 2 (KA2), aiming to improve lives of adults with intellectual disabilities by encouraging family therapeutic gardening and family therapeutic cooking as a way of supporting ongoing lifelong learning (LL) and independence of adult family members with intellectual disabilities (AFMID). Lifelong learning refers to all purposeful learning activities undertaken on an ongoing basis throughout a person's life, with the aim of improving knowledge, skills and competencies.

Project will last for 35 months in cooperation with non-profit organizations from Slovenia, UK, Croatia and Italy. Participating organizations are: Education Centre Geoss (Slovenia), Zveza Sozitje (Slovenia), Danilo Dolci (Italy), UOSIKAZU (Croatia) and Thrive (United Kingdome). With the implementation of the Family Education MeTURA partner organizations will expand their offer of lifelong learning opportunities for their participants - 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 give insights into the social and functional acquiring of competences and other therapeutic benefits of these activities.

In the phase of preparation of the MeTURA proposal, the project partners detected the need for skills that would enable educators to actively engage more vulnerable adults, especially families and adult family members with intellectual disorders (AFMID) in their involvement in LL programmes, social activation programs and participation in public events organized by partners and institutions of adult education. Their participation is often very low, despite the fact that participation in these programs is free of charge or in certain cases, participants get refurbished the costs of participating. O3 will explore the possibilities of effective motivation strategies for involvement of families and AFMID-vulnerable adults in LL, and strategies of preventing that participants leave the activity before its completion in conjunction with the acquired and necessary basic skills (mathematical and ICT skills, literacy). IO3 goals are:

- effective communication strategies of educators in their involvement in LL for adults, social activation;

- to find key inclusive communication system gaps and the necessary systematic and individual assistance infrastructure for integrating into the planned independent implementation of the LL in families;















- which methods of publishing, implementing and using supportive learning tools are most effective for target groups: printed, CD, movies, audio recordings, FB publications, web pages,...

- the methods and strategies for effectively disseminating and using the results of the project among the target groups of adults; where the target groups potentially perceive the greatest difficulties in accessing the results of the project;

- identify the necessary communication skills of educators, learning families and vulnerable adults, the content of psycho-education, including communication through social networks for more effective social activation.

Within the O3 Study, two questionnaires were created, one for educators and one for families with AFMID. The questionnaires were conducted in all participating countries.

With the questionnaire for educators, we first wanted to find out the motivational support methods carried out by educators in order to involve and interact with families and their adult family members with intellectual disorders.

Questionnaire was divided into two parts; the first part consisted of some general information about the family, the second part consisted of 12 closed and 6 open questions on the communication process between educators and families or educators and AMFID. In particular, the questionnaire highlighted the strategies used by the educators to get AMFID involved as well as the motivational techniques put into practice when working with AFMID. We also gave the educators the opportunity to express their own opinion and share their experience about LL activities with families with AFMID.

Similarly, the family questionnaire was divided into two sections; the first section consisted of some general information about the family while the second one consisted of 11 closed questions that were answered within the whole family. With the questionnaire for families, we first wanted to find out what kind of activities the families and AFMID attend. Second, we wanted to find out how they get in contact with educators and what are the reasons they attend some activities rather than others. Emphasizing on decision making process, we focused on how the family identify and thus decide to attend these activities together with their AFMID. Therefore, we wanted to find out if the families believe they would benefit from this kind of activities (gardening and cooking).















### 2. NATIONAL REPORT SLOVENIA

In today's changing society and the emergence of many innovations that reflect the continuing economic, technological, political, cultural and other changes in the world, it is essential for every person to educate all the time. Only this way we can develop personally and achieve the most in life.

The term lifelong learning itself indicates that this means learning from birth to death, so also in the adulthood. The concept Lifelong Learning (LL) addresses adult education in all its forms as an indispensable part of life-long education, not just as a supplement of initial education. Therefore, it is important that we educate people through whole life, in all stages of life and in different fields, not only formal (school learning) but also informal and casual. Promoting lifelong learning is essential for the development of everyone (individuals as well as society).

The systematic regulation of adult education in Slovenia is still deficient in spite of numerous concepts, ideas and proposals, so it is important to look for solutions to its changes. There is a need to improve adult learning opportunities and to bring them closer to quality learning programs, new approaches and methods of work, and evaluation of what has already been adopted knowledge and familiarize them with the options available to them.

An effective adult education system needs to find its place in the context of a lifelong strategy learning to improve access to the:

- labour market;
- social integration;
- prepare people for active aging;
- intercultural cooperation;
- language learning and
- increase participation of people of all ages, including the people with disabilities and other disadvantaged groups of people.

When it comes to educating people with disabilities there are two important processes that need to be mentioned, which take place in proportion through the process of education.

First, is the **integration process** which means: 'integration into environment/society to the fullest extent possible', and is the adaptation of persons with special needs to the environment/society.

The second process is **inclusion**, which is "adapting the environment/society to the said target group ". The process of education of persons with disabilities will be successful only if these two processes - integration and inclusion - are successful.















The system of adult education needs to be changed and upgraded, so adults with different disabilities can have adequate access and quality education.

### 2.1 LIFELONG LEARNING OF ADULTS WITH INTELLECTUAL DISABILITIES

As mentioned, constant learning is important to everyone. For persons with intellectual disabilities this bring more challenges, as they need more motivation for it. The reasons are: lower intellectual abilities and with that lower ability of predicting positive effects of learning, lower motivational sphere, which in normal circumstances directly stimulates activities; lack of self-initiative elements, lower research-oriented point of view.

People with intellectual disabilities need lifelong learning follow-up, as for everyone their educational opportunities and interests need to be taken into account.

Options for different forms of education should be such as to help them shape their lives, and in particular to encourage the processes of growing up (becoming an adult) and the role of the adult in the areas of partnership, work, residence and leisure.

Special andragogical work with adults with intellectual disabilities most commonly concerns two areas:

- supporting to overcome learning difficulties that a person has in the educational process due to their disability;
- assisting in the choice of the various options offered to these persons by the wider social environment, including full inclusion and participation.

### 2.2 GOOD PRACTICE EXAMPLES IN SLOVENIA

### CMEPIUS

The Centre of the Republic of Slovenia for Mobility and European Educational Training (CMEPIUS) is a public institution working in the field of international projects and international mobility. It was established in 2003 and performs two main tasks:

- co-ordinating the Erasmus+ programme I the field of education, training and sport;
- supporting development in education and training

Among others, CMEPIUS implemented a programme of Lifelong learning in the years 2007-2013. The goal of this programme was to enable LL; gaining new competencies and knowledge, and in this way participate in the development of society and economy. CMEPIUS is internationally oriented, so this programme connected Slovenia to other European educational systems.















The programme of LL was conducted in the frame of the following sector programmes:

- Comenius;
- Erasmus;
- Leonardo da Vinci;
- Grundtvig.

Two programmes for persons with disabilities were implemented in the Grundtvig sector programme:

- Possibilities of LL for adult persons with intellectual disabilities, which was implemented by CUDV Dolfke Boštjančič Draga;
- Integrational LL of adult persons with disabilities, which was implemented by Andragoški zavod Maribor.

Leonardo da Vinci has financed a LL project for persons with disabilities called *Personal and professional growth,* which was implemented by VIZ Višnja Gora. The purpose of the project was to enable persons with disabilities to live abroad and to learn about European union and how it operates.

In the purpose of LL for persons with disabilities, there were some projects implemented, which were financed by other European or national sources:

- DISNET e-study net for unemployed persons with disabilities, intended for better computer literacy for persons with disabilities (implemented by Andragoški zavod Maribor;
- Check and go e-base with no barriers for people in the company, intended for minimizing barriers and enabling access to employment for persons with disabilities (implemented by Andragoški zavod Maribor);
- Training for life success My step (UŽU-MK) and Become an advocate for persons with disabilities, intended for educating, learning and connecting people with disabilities on different levels of social life (implemented by Ljudska univerza, Zavod za kulturo in izobraževanje Slovenska Bistrica)

Projects of LL enable persons with disabilities to gain new knowledge and competencies, and at the same time offering learning for life – learn how to have a quality life, work and co-existence. It is the birth-to-death learning, which offers people with disabilities personal growth and development, and thus a better life.

Down side of projects like these is that they are not widely available; they are mostly carried out in organizations or institutions, which are implementing the project. Therefore, the persons who are already included in an institution or Occupational Activity Centres are the persons who are part of this projects. And the ones living at home and not attending any available















program, still have difficulties to participate in lifelong programs and project. That's way bringing lifelong learning to people's home is so important.

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### 2.4 EDUCATOR QUESTIONNAIRE SUMMARY

The majority of educators that participated in the questionnaire are female an have more than 10 years of experience in their work.

Most of the educators say it is easy to get in touch with families with AFMID. The main obstacles in communication with families with AFMID are that the parents are in denial about their child's condition and have unrealistic expectations. Most of the educators communicate with families personally or over the phone.

The most used method in engaging families with AFMID in LL activities is adapted communication and volunteer support. The most important features in effective communication with families with AFMID are patience, active listening and respect.

Educators say that the main problem in implementing LL activities is the unresponsiveness of the families. Training on new methodologies would be the kind of support the educators need to help improve implementing LL activities.

Most of the educators think that positive response and motivation are very important when involving families with AFMID in LL activities. The key for successful implementation of LL for families with AFMID in their home environment are small groups and implementing activities which help families to integrate in unfamiliar environment. that if the activities were conducted in a home environment, AFMID and families would be more involved in the activities















### 2.5 FAMILY QUESTIONNAIRE SUMMARY

All of the families that participated in the questionnaire have one family member with intellectual disability.

Most of the families attend weekend seminars, lectures and seminars in order to support their AFMID. Most of the families do not meet with educators who implement activities before the start of them. Most of the families get the information on educational activities by the educators and institutions. The families prefer being contacted by e-mail.

Most of the families say that lack of time is the biggest problem when engaged in LL activities. Families say that from a personal point of view, AFMID needs encouragement and sense of achievement during a learning activity. Socializing with other families and exchange of experiences is the kind of support that would help families with AFMID improve the educational activities.

Most of the families say that becoming more independent and improving their social skills are the main learning needs of AFMID.

Most of the families are satisfied with the services they get from institutions where their AFMID is included.

### **3 NATIONAL REPORT ITALY**

In national report Italy formal ways of education for adult persons with intellectual disabilities are first presented, what are their options after finishing formal education and the offer of lifelong learning for them. Last, the questionnaire results for Italy are presented. The questionnaire was conducted among educators (20 questionnaires) and families (10 questionnaires) that have Adult Family Members with Intellectual Disabilities (AFMID).

### 3.1 Schooling and training for adult persons with intellectual disabilities in Italy

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

In particular for disabled pupils this is stated in the Constitutional Court ruling No. 215/87 and by art. 24 of the UN Convention on the Rights of Persons with Disabilities, ratified by Italy with the I. n ° 18/09.

The right for education of persons with intellectual disabilities is ensured in the Constitution of Italy and in some other international documents that ensure this right:

- International pact on civic and political rights (1966),
- legally binding Convention on children's rights,















- Resolution on including disabled children and teens in general education systems Council of European Union (1990),
- Recommendation 6 on a coherent policy for people with disabilities Committee of ministers (1992),
- The Salamanca statement and framework for action on special needs education (1994) UN,

Attending school is obligatory and free for all children and young people aged 6 to 16 who live in Italy. Pupils with disabilities can complete their compulsory education up to 18 years of age.

The children who have a certified disability have the right, and not just a simple possibility, to enrol in the nursery. Moreover, children who are certified in a situation of gravity (in accordance with paragraph 3d of art. 3d Law No. 104 of 1992) have the right to priority in the access to the public services of the municipal nests of 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 in Italy. To enable the inclusion of pupils with disabilities, the school must guarantee specific and additional resources, based on the needs of each student:

- 1. specialized support teacher;
- 2. autonomy and communication assistant;

3. basic assistant (personal hygiene with respect to the gender of the student, transfers within the school).

Students with disabilities can also:

1. have more time to do verification tests or do them in ways other than their companions;

2. follow personalized programmes, even different from those of the companions;

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

### 3.3 Lifelong learning for persons with intellectual disabilities

With regard to the possibility of orientation and professional training for people with mental disabilities, the Italian situation is complex, differentiated and often unsatisfactory. In a reality better than the current one, adolescents with intellectual disabilities after middle school should have the possibility of attending professional schools with staff resources and with adequate teachers to promote the integration of people with mental retardation. 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 the 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 very well organized and avant-garde realities: it is however a minority.

Taking note of this widespread lack, it must however be emphasized that since the years around 1970 Italy has favoured experiences of orientation, professional qualification and cutting-edge work placement (Montobbio and Casapietra, 1982; Neri and Brotini, 1982; Ravaccia, 1982, Bolpin, Schena and Zeffiro, 1986, Barbieri, D'Angelo, Oriani and Palmonari, 1987, Bonaconsa, Fattorelli, Fichera and Schena, 1988, Montobbio, 1982, 1985, 1989, 1999, Moderato and Paltrinieri, 1989; Moniga and Vianello, 1994, 1996; Causin and De Pieri, 1999; Breda, 2001; Cassullo, 2001; Mainardi, 2001; Vianello, 2006). 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 on the subject did not provide for interventions in favour of people with disabilities. With the L. n. 118/71 the first indications are given and, then, with the L. n. 845/78, more specific provisions in this regard, such as the coherence between the vocational training system and the general education system, the professional qualification of the disabled and the disabled, the interventions necessary to ensure them the right to vocational training, direct training initiatives to the professional reeducation of workers who have become disabled and the formation of individuals who are not fit to attend normal courses. The L. n. 104/92 then intervenes to integrate what has already been provided.

It provides that the Regions guarantee disabled students who are not able to use ordinary learning methods to acquire a qualification also through specific activities within the activities of the vocational training centre, taking into account the orientation that emerged from the educational plans individualized during the scholastic process. To this end, they 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 pretraining courses. However, there is no support or only a few hours.

A very important law for people with disabilities in Italy was approved in 1992, the famous "104 Law". First of all, what is the law 104: The law 5 February 1992 n. 104, better known as law 104/92, is the legislative reference "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. The assumption is in fact 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, technical help.

After its entry into force, Law 104 was updated in some parts, as a result of rules introduced later. Article 12 of Law 104 guarantees the right to education and education of the disabled person in the nursery school sections, in the common classes of educational institutions of all levels and in university institutions. The exercise of the right to education and education cannot be prevented by learning difficulties or other difficulties deriving from disabilities connected with disability.

Article 17, on the other hand, concerns PROFESSIONAL TRAINING, according to which it is the Regions that implement the insertion of the disabled person in the ordinary courses of professional training of public and private centres and guarantee handicapped students who are not able to use the methods of ordinary learning the acquisition of a qualification also through specific activities within the activities of the vocational training centre taking into account the orientation that emerged from the individualized educational plans realized during the scholastic process.

The vocational training courses must take into account the different abilities and needs of the disabled person who, consequently, is inserted in common classes or in specific 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%).















We are therefore pleased to report an important new opportunity for those who are disabled and looking for work: the new call launched by 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, and that gave a job to 80 young people with disabilities (5 for each of the 16 participating regions).

THE PROJECT - 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 participants 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 mode. 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 access to 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 Educators questionnaire summary

According to the results, the educators that participated in the questionnaires were mainly men (55%). According to them, mistrust, lack of social media and socio-economic hardship constitute the many obstacles in communicating with families. The vast majority of respondents communicate with parents over the phone or personally. Most used methods by educators are adapted communications and peer support while "respect", "patience", "open mindness" and "listening" represent the most important features in the communication process with AMFID. According to 65% of the educators, families are not responsive and this constitutes an obstacle to LL activities. Furthermore, educators had difficulties getting in touch with families. In Italy, training on new methodologies would constitute an helpful support for educators. Most of respondents, affirmed that the educator should be clear,















simple, empathetic, cordial and have empathy and predisposition to communication.

### 3.6 FAMILY QUESTIONNAIRE SUMMARY

90% of interviewed families have one adult wit learning disorder within their household (one family has 2 AFMID). most of the families participate in meetings to share experience, parents club, children and families club. in Italy 100 % of the total of the respondents would rather meet the educators, at least 2 times before the beginning of the educational activities. It is worth noting that rarely the educational activities are chosen by the parents, excluding the AFMID or the educators.

Most of the families get the information on educational activities by the educators and institutions as well as by word of mouth. Families also answered that they prefer being contacted by phone.

According to the majority of respondents, AFMID needs confidence during a learning activity. Furthermore, socializing with other families and exchange of experiences would improve the educational activities they participate in. In conclusion, becoming more independent (100%) and get knowledge through informal activities were the main learning needs identified by families.

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### **4 NATIONAL REPORT CROATIA**

In our national report, we present a system of education and training for adults with intellectual disabilities in Croatia through a legal obligation, processes of deinstitutionalization of people with intellectual disabilities and returning to the families or residential communities that give them more opportunities for lifelong learning. Adverse factors that make it difficult for families and their adult members with intellectual disabilities to more actively live in the community are described too. We also present the motivational methods of educators for more effective social activation of families and their adult members with intellectual disabilities. Finally, the results of the questionnaire for Croatia are presented. The questionnaire was conducted among educators (20 questionnaires) and families (10 questionnaires) with adult members with intellectual disabilities (AFMID).

# 4.1 SYSTEM OF EDUCATION AND TRAINING OF ADULTS WITH INTELLECTUAL DISABILITIES IN CROATIA

The education system in Croatia begins with pre-schools that include local government kindergartens and private kindergartens (individuals, religious communities and associations) and institutions such as libraries, various associations and elementary schools where pre-school programs and shorter programs are implemented.

Primary education is compulsory and free of charge for all children between the ages of 6 and 15, and for children with major disabilities up to 21 years of age. Specific programs relate to the education of children with disabilities and alternative curricula, and for those over 15 who have not completed primary school there is a system of basic adult education. The provisions of the Law on Education in Primary and Secondary School stipulate:

### Article 62

(1) Students with special educational needs are gifted students and students with disabilities.

(2) The education of students with special educational needs shall be conducted in accordance with this Act, unless otherwise provided by special regulations.

Article 65

(1) Students with disabilities are:

- Students with disabilities,

- Students with learning disabilities, behavioural problems and emotional problems,















- Students with disabilities due to educational, social, economic, cultural and linguistic factors.

The Adult Education Act, whose General Provisions under Article 1 provide:

(1) Adult education encompasses the entirety of the adult learning process intended to:

- exercise the right to the free development of personality,

- train for employability: acquire qualifications for the first occupation, retrain, acquire and deepen professional knowledge, skills and abilities,

- Train for active citizenship.

(2) Adult education is part of the unique education system of the Republic of Croatia.

Adult education is an important subsystem of the comprehensive education system. It enables the adult to acquire general and professional education in various fields, for example in the natural, technical, social, humanistic, artistic and other. Adults acquire education through formal (formally structured, curriculum, teacher / educator guidance, gaining formal certification), non-formal (intentional learning from a person's point of view to gain knowledge, develop abilities and skills, but without a public document) and informal learning (not organized or structured according to goals, learning time, or support).

People with intellectual disabilities often drop out of school and do not continue their education because of discriminatory attitudes and lack of personalized programs and support. Because most lifelong programs and materials are not accessible to them, adults with intellectual disabilities are systematically denied the opportunity to continue developing skills and competencies throughout their lives.

The Convention on the Rights of Persons with Disabilities also obliges States Parties, and Croatia is one of them, through Article 24 relating to education, to recognize the right of persons with disabilities to education. In order to exercise this right without discrimination and on the basis of equal opportunity, States Parties shall ensure the inclusiveness of the education system as well as lifelong education.

# 4.2 DEINSTITUTIONALIZATION PROCESS OF ADULTS WITH INTELLECTUAL DISABILITIES

People with intellectual disabilities throughout history have been largely degraded and disenfranchised, often labelled deviant and undesirable and have been singled out as such. Until the mid-twentieth century, they were mostly covered solely by the segregation treatment system.















The 1960s saw a significant change in the approach to and interpretation of disability; the medical model of disability is gradually being transformed into a social model. In addition to the social model, a human rights model was being developed, in which the aim is not only to achieve legal equality but to act on the empowerment of persons with disabilities in order to develop their potential.

People with intellectual disabilities in the institutional care system have not had, and do not have, sufficient opportunities to perform meaningful activities of daily living and develop maximum potential due to objective circumstances, including insufficient staff support. In Croatia, the process of deinstitutionalization and inclusion of people with intellectual disabilities in community-supported housing is ongoing, providing lifelong learning through practical activities. In such model of organized housing, a person should be involved in all household tasks, and thus in the process of daily meal preparation. Learning to take care of oneself, the skills of daily living are especially important for adults with intellectual disabilities in the context of their better fulfilment of adult roles. In order for an adult with intellectual disabilities to have a better quality of life, it is very important to enable them to acquire practical skills and to focus their rehabilitation on strengthening their independence and autonomy.

Contemporary goals for the rehabilitation of people with intellectual disabilities include the principle of normalization, social integration, individualization, orientation to meeting needs, encouraging independence and autonomy. Normalization as a concept emerged in the 1970s and includes the right of a person to live in an environment that provides him/her with adequate support to reach his or her life potential as the rest of the population, and includes reaching the role of adulthood. Within the concept of normalization, there is a principle of activities appropriate for the age of the person, which states that the activities engaged in by a person with intellectual disabilities, the way of dressing and interacting with the person, should be in accordance with his or hers chronological age. This principle also implies the provision of services that are consistent with a person's chronological age. This reduces the ability to view people with intellectual disabilities as "forever children".

# 4.3 LIFE IN THE COMMUNITY OF THE FAMILY AND THEIR ADULT MEMBERS WITH INTELLECTUAL DISABILITIES

Over time, the child grows up to be an adult with intellectual disabilities. Many changes happen, but that person still depends on the care of their family members, most notably their parents. One effective way for parents to reduce their tension, frustration, and anxiety is to have quality support and education during the growing up period of the person with intellectual disabilities. Caring for an adult member with intellectual disabilities always















brings with it new challenges, which is why it is necessary to constantly adopt new information through various educations that contribute to a better everyday life. Because parents are the sole or greatest support for a person with intellectual disability, it happens with the best of intentions that they have the need to act over protectively. The other extreme is that they are too lenient with their dependent member, which can have opposite effects on what parents want to achieve.

A person with intellectual disabilities can gain a lot from a quality relationship with their parents and progress through development. Parents can contribute to the well-being of their dependent members through daily activities without forgetting parental love, tenderness and warmth. It is good to encourage communication between a dependent member with intellectual disabilities and other family members, but it is important to always keep in mind that family members without disabilities and siblings must have their own friends and hobbies as well as their own time with their parents.

The purpose of supporting parents and other family members is to better understand and accept the life situation, to more rationally accept the role in it, as well as the role of other family members, the complexity of problem solving, the specificity of expressing and meeting the needs of a member with intellectual disabilities.

# 4.4 MOTIVATIONAL METHODS OF EDUCATORS FOR MORE EFFECTIVE SOCIAL ACTIVATION OF FAMILIES AND THEIR ADULT MEMBERS WITH INTELLECTUAL DISABILITIES

Rapid and frequent changes in the world require the lifelong development of the personal, social and professional competences of individuals, and thus are contemporary societies facing the necessary changes in the field of education. It must be modified in accordance with the requirements of society and individuals (education for life and work) in terms of the value system and the real needs of the labour market. Adult education is not exempt from the processes that happen around us.

Motivation is a key factor in a successful lifelong learning process and should therefore be viewed through the links between educational goals, expected outcomes, methods of evaluating knowledge, skills and abilities. It is also the role of the educator to stimulate the natural motivation of families and their adult members with intellectual disabilities, taking into account their needs, interests and emotions, using appropriate motivational techniques.

Motivational techniques should be present in all parts of the adult education process:

 getting to know the students and introducing them to the curriculum (different ways of getting to know the students, "breaking the ice")















- adopting, identifying and repeating teaching content (interactive teaching methods, collaborative learning strategies)
- Monitoring and evaluation (competitions, quizzes)

### 4.5 QUESTIONNAIRE SUMMARY

### Educators

Although majority responded that it was easy to contact families with AFMID, 45% of educators faced difficulties in contacting those families. The main reasons why educators cannot reach families are lack of interest, closed nature of the family and lack of time. 65% of educators prefer to personally contact families with AFMID. It is worth noting that few use e-mail and social media to communicate with these families. 95% of educators get acquainted with family and AFMID before beginning activities. In the process of communicating with AFMID, the main features of educators should be "respect", "listening" and "patience". When confronted with a problem in an activity, educators prefer to address it with their families and with AFMID (90%). 25% of educators involve other family members to solve the problem.

Most educators (75%) would benefit from training on new methodologies to refine, and 70% felt that more motivational techniques would help them. 55% of educators think that if the activities were conducted in a home environment, AFMID and families would be more involved in the activities. On the other hand, 35% of educators answered negatively.

### Families

70% of families meet with educators before starting educational activities, while 30% do not. 5 families who meet with educators do it as needed, and 3 families do it once a month. Educational activities are not selected by parents on their own, but include AFMID or educators. About 60% of families are informed about educational activities via the Internet, and 40% via TV or radio, and by word of mouth. Only 30% of families receive information from educators / institutions and through social networks. Most families (60%) prefer personal or telephone contact with institutions. Lack of time, too many participants and financial difficulties are the biggest problems for families who engage in lifelong learning activities. 80% of families responded that sharing experiences would enhance the educators, which was answered by 50% of families.

On the needs of AFMIDs learning, most families responded with "to become more independent" (60%), while 50% of families identified greater involvement in the local community as one of the most important needs of AFMIDs.















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### **5 NATIONAL REPORT UNITED KINGDOM**

In this report, we initially discuss the routes and opportunities for formal education for adults with learning disabilities in the UK. We then discuss the options available to them after finishing formal education and the ongoing opportunities for lifelong learning. We also look at the activities in the UK that adults with learning disabilities are most often engaged in. Lastly, we present the questionnaire results for the UK. The questionnaire was conducted among educators (20 questionnaires) and families (21 questionnaires) that have Adult Family Members with Intellectual Disabilities (AFMID).

# 5.1 SCHOOLING AND TRAINING FOR ADULTS WITH LEARNING DISABILITIES IN THE UK

The education system in the UK is divided into four main parts, primary education, secondary education, further education and higher education. Children in the UK have to legally attend primary and secondary education which runs from about 5 years old until the student is 16 years old.

It wasn't until 1970 that disabled children – previously classed as being unable to be educated – were given a right to participate in education.

However, the law has changed substantially since then: Protocol 1, Article 2 of the Human Rights Act, Article 28 of the UN Convention on the Rights of the Child, and Article 24 of the UN Convention on the Rights of Persons with Disabilities all state the right of disabled people to receive an education.

Young people, with or without a learning disability, must now be in education or training until at least the age of 16. In England, they must then do one of the following until they are 18:

- stay in full-time education, e.g. at a college
- start an apprenticeship or traineeship
- work or volunteer (for 20 hours or more a week) while in part-time education or training.

### **5.2 SCHOOLING FOR INCLUSION**

Pupils considered to have "special educational needs" (this does not include all disabled children) should be included in mainstream schools provided that this does not conflict with parental wishes or affect the efficient education of other children (section 316 of the Education Act 1996, as amended by the Special Educational Needs and Disability Act 2001).

There is however an additional right to parents of disabled children to veto the inclusive education their child has a right to if they feel that is what is best for them, and instead school them in a specialist setting.

The Children and Families Act 2014 provides for the special educational needs and disability (SEND) support system in England, covering education, health and social care.















SEN support is support given to a child or young person in their pre-school, school or college. In schools, it replaces the previously existing 'School Action' and 'School Action Plus' systems. For children of compulsory school age the type of support provided might include extra help from a teacher, help communicating with other children, or support with physical or personal care difficulties.

In 2006, the "disability equality duty" came into force, as introduced by the Disability Discrimination Act 2005. This puts a general duty on public authorities – including schools and further and higher education institutions – to promote disability equality. Schools must have regard to the need to:

- promote equality of opportunity between disabled and other people;
- eliminate discrimination and harassment, promote positive attitudes to disabled people;
- encourage participation by disabled people in public life; and
- take steps to meet disabled people's needs, even if this requires more favourable treatment.

### 5.3 LIFELONG LEARINGING FOR PEOPLE WITH LEARNING DISABILITIES

In England, the Education and Skills Funding Agency (ESFA) funds schools and academies with sixth forms, further education colleges and special post-16 institutions. The funding is provided to these institutions for the education and training of learners aged between 16 and 19 years and up to the age of 25 for young people with an Education, Health and Care (EHC) plan, depending on the needs specified in the plan.

If you have an EHC plan, you may be still be eligible for funding up to age 25 but there is no automatic entitlement to education provision. What is funded will depend on the outcomes and needs specified in your EHC plan, and the decision of your Local Authority. The Local Authority has to consider if the college suits your needs and if it is an 'efficient use of resources'.

Beyond 25 years of age, funding to gain access to further learning may come from an individual's benefits as provided by the government/local authority or the charity sector.

### 5.4 Some examples of activities carried out by families with AFMID in the UK

While there have been improvements in social inclusion culturally, there is still a long way to go for those with disabilities and learning disabilities in becoming entirely accepted into societal norms.

A report carried out in 2008 by Eric Emerson and Chris Hatton for the Centre of Disability Research and backed by Mencap collected findings on how people with disabilities were able to spend leisure time.















Table 7: Participation in Preceding Month in Community Activities						
	Mild or moderate	Severe	Profound multiple	All people		
People living in private households						
Been shopping	88%	90%	73%	88%		
Visited friends or family	83%	83%	70%	82%		
Eaten out in a restaurant, pub or café	61%	75%	50%	67%		
Been to a pub or club	55%	60%	36%	56%		
Been to the hairdresser	53%	53%	50%	53%		
Played sport or gone swimming	39%	48%	36%	43%		
Been to the cinema, play or concert	34%	40%	23%	36%		
Been to the library	25%	18%	9%	21%		
Watch a sporting event	23%	17%	8%	20%		
Done none or only one of these things	4%	4%	17%	5%		
People living in supported accommodation						
Been shopping	91%	91%	81%	90%		
Visited friends or family	73%	61%	44%	65%		
Eaten out in a restaurant, pub or café	76%	83%	79%	80%		
Been to a pub or club	70%	80%	66%	75%		
Been to the hairdresser	71%	76%	75%	74%		
Played sport or gone swimming	37%	38%	33%	38%		
Been to the cinema, play or concert	47%	51%	30%	47%		
Been to the library	30%	19%	6%	23%		
Watch a sporting event	22%	18%	8%	19%		
Done none or only one of these things	3%	4%	9%	4%		

The social participation of disabled people is the biggest and most difficult challenge to face, because in it there are added problems deriving not only from the subject's disability condition, but above all and mainly from the environmental and cultural context. There are no official statistics on the activities carried out by families with AFMID as the LL opportunities are quite fragmented and regions in Italy have the special right to make laws in this sector so data are not global and valid at national level. According to ISTAT, the Italian Institute for Statistics, 22% of disabled people under the age of 44 goes to the cinema, theatre or to see various shows in the last 12 months, compared to 31% of non-disabled. 20% of disabled people reads books. 26% of disabled people practices sports and 60% of these is between the ages of six and 44. The prevailing reason of the sporting activity remains the entertainment up to 64 years, only after the therapeutic purpose of the activity takes over. The number of disabled people enrolled in the Disabled Sports Federation increased in the period 1989-1997 with the same pace as sports clubs, averaging about 5.3 percentage points (26). The quality of services offered by sports clubs has improved: in less than a decade, in fact,















we have gone from an average of six operators per sports company in 1989 to an average of fourteen operators in 1997.

### LITERATURE

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### **5.5 QUESTIONNAIRE SUMMARY**

### The educators

The educators reported that as well as practical issues with contacting families of adults with LD, there is also an increasing drive to help AFMID to be as independent as possible and many institutions seek to promote this. Adults with LD may be referred via social or community organisations rather than with family involvement. Parents are often working so are not available during work hours (either to be involved in activities or to be consulted) and in some cases families are not in the same area as the AFMID.

Main channels of communication are traditional methods such as via personal contact or over the phone and most activity selection and behaviour regulation are done directly with the AFMID rather that by involving families. Consent form the AFMID is often sought/required before discussing things with the family.

Educators are keen to have more support and resources for delivering activities whilst personal difficulties and transportation tend to be the main reason that AFMID are not involved. Educators thought that they may be more engagement in activities if they could be carried out in the home environment, but it would depend on the family and the activity. Activities need to be simple and relevant to daily life.















### The families

Most activities that are available are for adults with LD only apart from things such as family support groups and educational activities where the adult with LD is often accompanied by a family member. In some areas there are no activities available that are suitable for the adult with LD and a lack of understanding of the issues by educators/activity providers was highlighted as an issue. The majority of families do not meet directly with educators/activity providers, but activities are sometimes organised via secondary contacts such as support workers or support organisations for adults with LD. Even where there is contact with educators, this is not frequent (more frequent contact may be occurred in formal educational settings such as colleges than with community activity providers). In general, the AFMID chooses the activities that they want to attend but the parent may make these decisions where the AFMID lacks the capacity to do so.

Information about activities is usually obtained informally via word of mouth or browsing internet/social media or through leaflets or contact organisations/information providers for adults with LD. Email (mailing lists) and leaflets are the preferred method of contact. Families thought that activities were not advertised via the right communication channels and that care providers, LD social care services and information providers for adults with LD would be good routes to advertise (NOTE – it's likely that this is because they are trusted services, as is advice and recommendations from others with LD).

Main issues in engaging with activities were lack of understanding from educators of the disability and communication difficulties, although one respondent said that they had no issues and educators were already doing enough. Families thought that the best way to improve educational activities would be to make them social with other families and having courses delivered & supported by individual s with expert knowledge of the disability and how to work with individuals with LD.

The main learning needs are independence, social skills and community involvement. This makes sense in context of the general move to enable AFMID to live independently in the community (as does the importance of financial and cooking skills) qualifications and functional skills were seen as less important. Other needs mentioned relate to being able to do and feel like any other member of society. It was also suggested that more services needed to work on the Social Model of Disability. 50% of families were happy with the service they received and 50% were not and suggested the best way that they could be improved was by providing services in all areas and ensuring tutors have the understanding of the needs of AFMID and how best to work with them.















### 6. CONCLUSIONS

### EDUCATOR QUESTIONNAIRE

Apart from Italy, the significant majority of educators that participated in the questionnaire where female.

Although majority responded that it was easy to contact families with AFMID, educators participating in the questionnaires in Croatia and Italy faced difficulties in contacting those families. According to educators, lack of interest, closed nature of the family and lack of time and social media as well as the denial about their child's condition represented the main obstacles to reach families with AFMID.

As reported by educators in all partner countries, the main channels of communication used with families with AMFID are over the phone or personally; most adopted methods by respondents are adapted communication, peer and volunteer support.

In order to successfully work with AFMID, the vast majority of educators identified the following features: patience, active listening, respect, openmindedness.

Moreover, questionnaire's results revealed that families are often not responsive and this constitutes an obstacle for educators when implementing LL activities. Furthermore, educators had difficulties getting in touch with families. When confronted with a problem in LL activities, educators that participated in the questionnaire include the whole family in problem solving. According to respondents, training on new methodologies, more resources and more support staff would help them to improve their activities.

Educators were also asked to identify the elements for an effective communication strategy when involving families with AFMID in LL activities. In this regard, most common answers were empathy and predisposition to communication. In addition to this, to communicate successfully with such families, the educator should be clear, simple, empathetic and cordial.

Concerning the development of an effective guided implementation of activities for family in their home environment, respondents identified different factors. According to Slovenian educators, small groups are key when implementing LL activities for families with AFMID in their home environment. Such activities should also help families to integrate in unfamiliar environment. In Italy, the family play an active role and they should be guided and accompanied, at least during the first period. In Croatia respondents thought that they may be more engaged in activities if they could be carried out in the home environment. According to British educators, activities need to be simple and relevant to daily life.















### FAMILY QUESTIONNAIRE SUMMARY

All of the families that participated in the questionnaire have one family member with intellectual disability.

The majority of respondents have one family member with intellectual disability. Some families attend weekend seminars, lectures and seminars in order to support their AFMID while others participate in meetings to share experience, parents club, children and families club.

It is worth noting that in Slovenia most of the families do not meet with educators who implement activities before the start of them while in Croatia (70%) and Italy (100 %) the respondents would rather meet them. In the UK, the majority of families do not meet directly with educators but there may be secondary discussions with support workers or organisations to identify options for the coming year.

Unless the AFMID lacks the capacity to do so, the educational activities are usually chosen by the AFMID, including the family or the educators.

Most of the times, families get informed on learning and educational activities by the educators and institutions as well as by word of mouth. Families are informed about educational activities via the Internet/social media.

Questionnaire results showed that families prefer being contacted by e-mail or by phone.

Lack of time represents the biggest problem for families engaged in LL activities while most of them faced financial difficulties in accessing these activities. Furthermore, lack of understanding from educators of the disability and communication difficulties constituted one of the main issues for families when engaging with LL activities.

According to respondents, AFMID needs confidence, encouragement and sense of achievement during a learning activity.

The majority of families reported that socializing with other families and exchange of experiences would improve the educational activities they participate in. Respondents would also be keen on receiving support by an expert knowing how to work with individuals with LD.

Results of the questionnaire show similar situation in all participating countries about the learning needs of the AFMID. Independence, social skills and community involvement were selected as the main learning needs for concerned members of the family that participated in the questionnaire.









