

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



## **SYNTHESIS REPORT**

**Activity O1, A study of the opportunities for lifelong learning for families and their adult family members with intellectual disabilities in the concept of bringing the lifelong learning offer to their home**

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 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 Sožitje (Slovenia), Danilo Dolci (Italy), UOSIKAZU (Croatia) and Thrive (United Kingdom). 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 pre-preparations project partners discovered that the majority of adult persons with intellectual disabilities live at home with their families and that each family would benefit from a personalized, to them adapted, process of lifelong learning. O1 study's intention was to explore opportunities for lifelong learning for families and AFMID in their home environment. The intention of the study is to provide information useful for development of new knowledge and andragogic tools for educators who will be able to develop, based on the research results, a Family education MeTURA – Back to the roots method for implementation of therapeutic family gardening and therapeutic family cooking for more independent life of adult family members with intellectual disabilities.

Within the O1 Study, a questionnaire was conducted in all participating countries. With the questionnaire, we first wanted to find out if the families and AFMID attend any educational or other activities and which ones and second, we wanted to find out what are the reasons for not attending activities. Emphasize was on finding out if the family is willing to attend activities together with their AFMID (adult family members with intellectual disabilities) and in specific, if the activities of therapeutic gardening and cooking would be interesting for families and AFMID to attend. We wanted to find out if the families believe they would benefit from this kind of activities (gardening and cooking) and in what way.

Questionnaire was divided into three parts; first part consisted of some general information on the family, second part consisted of 12 closed questions that were answered within the whole family, while the third part consisted of one open and 3 closed questions and was meant for AFMID and was prepared in easy to read from.

## 2 NATIONAL REPORT SLOVENIA

In national report for Slovenia 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, questionnaire result for Slovenia are presented. The questionnaire was conducted among families that have adult family members with intellectual disabilities (AFMID).

### 2.1 Schooling and training for adult persons with intellectual disabilities

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

- Convention on the Rights of Persons with Disabilities – United Nations (2006, ratified by Slovenia in 2007),
- 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,
- international - legal document ratified by the Slovenian parliament on 15. 4. 2008: Convention on rights of disabled (article 24. – the right to education).

Students with intellectual disabilities can never be completely independent although their independence can be improved with special educational processes. Schooling is slower and has different course than regular schooling. Students with intellectual disabilities also need many encouragements for their personal development.

In assessing the limits of the student's work, many factors need to be considered:

- cultural environment and peers,
- cultural and linguistic diversity, diversity in communication, the factors of senses, movement and behavior,
- in each individual there are always limits and strong areas,
- a description of constraints or weaknesses and also strong areas of individual is important in order to develop the necessary assistance system,
- with the appropriate form of assistance, life of people with intellectual disabilities generally improves over a longer period of time.

Special education program for persons with intellectual disabilities in Slovenia divide into:

- **obligatory part**, lasting 9 years and has 3 degrees: first (I), second (II), and third (III). Each degree has 3 years of schooling, and it lasts until the persons age of 18. Obligatory part can be followed by an optional program, lasting 3 years and includes fourth (IV) degree of schooling.
- **follow up** (optional) **program** from the age 18. – 26., lasting eight years, titled **Learning for life and work** and includes fifth (V) and sixth (VI) degree of schooling. V. degree lasts 3 years and VI. degree lasts 5 years (Republic of Slovenia, Ministry of education, science and sport, 2014).

Students finish obligatory schooling when they attend the program on I, II and III degree, for three years on each degree. When they finish 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 estimated level of achieved development, description of their knowledge, and suggestions for their successful inclusion in life and work.

Within our project, we are emphasizing on adult persons with intellectual disabilities. Adult persons with intellectual disabilities are persons who have an important limitation of both intellectual capability and adapted behavior, which is reflected in the conceptual, social and practical adaptation skills.

Person with intellectual disability has lower abilities in at least two of the following areas of adaptive behavior:

- communication,
- self-care,
- self-directedness,
- health and safety,
- housework,
- free time,
- work and employment,
- functional academic knowledge,
- social interdisciplinary ability.

The area of education for adult persons with intellectual disabilities in Slovenia still needs to be improved. Often their wishes, needs and interest for further education are being neglected. Like all persons, persons with intellectual disabilities differ in their capabilities and that is why they need individual approach that includes the needs and capabilities of each individual.

For education of adult persons with intellectual disabilities in Slovenia there is an official verified special program of V. degree (for persons age between 18 – 21) that is performed like an optional program, and program learning for life and work (VI. degree), (for persons age between 21 and 26).

## **2.2 Principles and goals of the program from the age 18. – 26.learning for life and work**

Program is prepared with the intention to continue with the education of adults with intellectual disabilities and to prepare them as much as possible for their independent life and work. The program's aim is to teach them simple chores and include them in social life. Emphasis is on the education of adults that is why the program takes into account the principles and values that are used in education processes for adults; ensuring rights for self-realization and high quality of life. This rights can be achieved only with continue education, with which they improve their knowledge, abilities, competences. In this way they can overcome obstacles, lower their disadvantages and their disabilities. When organizing the education process, the individual has to be seen as a grown up person, their educational needs have to be taken into account.

The purpose of this program is that adult persons with intellectual disabilities upgrade their knowledge and skills gained on previous stages of their education. Contents from different educational areas must be at all time related to the context of social environments. This means, that a big part of the content should be practical with the intention to achieve success and greater independence of these persons for their successful inclusion in work and life.

### **Principles:**

- learning and education of persons with intellectual disabilities is not just needed and sensible, but it is their right,
- continuing inclusion in school system and education, that offers systematic ongoing education and training,
- inclusion and integration,
- functionality of education and focus on solving real life problems with gained knowledge,
- interdisciplinary and team work,
- Individualized approach.

### **Goals:**

- to encourage optimal development of positive personal characteristics and their capabilities on mental, emotional, speech, social and employment area,
- prepare them for active and independent inclusion in the social environment with the use of social rules and communication abilities,



- to educate and learn for socially acceptable conduct,
- to prepare them for independent life by including the right of choice, development of self-respect, positive self-image and developing capabilities for resolving conflict situations,
- gaining and strengthening basic knowledge in the area of general knowledge, developing and keeping their independence, work and employment technique, creative knowledge, sport and recreation, learning how to actively spend their free time, learning about self-advocacy and active citizenship, intimate life and sexuality,
- develop and deepen elements of work ethic: working skills and habits, persistence, punctuality, working discipline, work rhythm, understanding and following instructions, get to know and use different tools and materials, adjust them for independent work and planning of work, adjust to rational use of material, to have organized working space, to develop skills and habits for different house chores, to take care of own safety, to develop elements of production process and adjust to work production,
- to develop contents of elementary life areas, that ensure development and quality of life of persons with disabilities (Republic of Slovenia, Ministry of education, science and sport, 2014).

From the age of 18., persons with intellectual disabilities can get involved in an Occupational Activity Center<sup>1</sup> (they cannot be included in schooling and Occupational Activity Center at the same time). Occupational Activity Centers are public institutions. Their services last until there are reasons for and individual to be included in this kind of institutions and until he/she is ready to accept services. Their inclusion can be temporarily or occasionally when it is periodically repeated for a specific time.

Occupational Activity Centers start to perform their services in the morning time for 8 hours daily, from Monday through Friday. They can also offer some other activities, outside this schedule, like attending sport and cultural events, winter, summer holidays, etc.

Occupational Activity Centers cover services of:

- **basic care**, which can include accommodation, food, technical care and transportation,
- **social care** which includes three aspects;
  1. guidance: organizing and performing individual programs, refreshing and upgrading existing knowledge, skills, developing social skills, cognitive capabilities of individuals and developing greater independence,

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<sup>1</sup> In Slovenian language called *Varstveno delovni center*.

2. protection: guidance, support and offering a feeling of safety, helping with personal hygiene, help with physiological needs, help getting dressed, communicating, etc.

3. employment under special circumstances: forms of work that help the persons to keep their gained knowledge and learn new skills. The income is divided, as a prize, among the persons included in an Occupational Activity Center and spent for better quality of work and living (Social protection institute of the Republic of Slovenia, 2017).

### **2.3 Lifelong learning for persons with intellectual disabilities**

In today's fast changing society the ongoing education is necessary for every person. Only with ongoing education, the person can follow new technology, attend social life as an active citizen and can be active until late ages.

Interest for reading, writing and other activities with the persons with intellectual disabilities often appears after the age of 20. Motivation for learning increases, as well learning capabilities, persons become more flexible, they easier resemble conduct of others and are more open for social inclusion (Kuplen 2018).

When referring to lifelong education for persons with intellectual disabilities we have to pay attention that communication with them has to be like with other adult persons and that the used learning materials are prepared for adults. It is important to create situations in which persons feel independent, in which their dignity stays intact and that professionals are responsible when exercising their authority.

Lifelong learning for persons with intellectual disabilities includes:

- keeping and developing their social skills,
- keeping their gained knowledge, skills, habits,
- achieving and keeping their psychophysical condition,
- keeping and developing their independence,
- whole / systematical approach (Golob 1998).

and has two goals:

- to provide learning through their whole life,
- to help them include in broader social environment.

The overall goal is, that persons with intellectual disabilities, with further education, expand their knowledge and gain social skills, strengthen their

independence, form self-trust and have possibilities to meet with others (Novljan and Jelenc, 2000).

Education process has to take into account real level of development and real capabilities of these persons. We have to be aware at all time that they are able to improve their independence through learning, and when their social processes are being systematically encouraged.

In their adult period the appropriate usage of their free time and work is very important. Activities that help them build new experiences are for example:

- learn about how to shop for food and prepare meals,
- how to behave in restaurants,
- how to treat friends and other people,
- how to stay healthy,
- how to actively spend their free time.

This topics show that education for persons with intellectual disabilities differ from education of other adult persons. For example art class means for them more than just painting, but as well a well spent day with friends. Programs should not include just topics that are interesting for an individual, but as well topics for developing personal and social capabilities of an individual.

Education for adults with intellectual disabilities should include all adult persons with intellectual disabilities, but this does not mean that each institution should have a special program for them. It is better that education takes place outside of the institutions and is available to those persons who live at home as well. We have to consider individuals will, interests, provide mutual communication (Novljan and Jelenc, 2000).

In Slovenia, the area of lifelong learning for persons with intellectual disabilities is included in the area 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.). Meaning that the need for further education or lifelong learning of these persons is within 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, persons with disabilities have the right to social inclusion services provided by providers of social inclusion services in the community with regard to the equal coexistence of people with disabilities and non-disabled persons in the community. The Article 10. specifically mentions Lifelong learning as a service of Social Inclusion.

Persons with intellectual disabilities in Slovenia can attend lifelong learning mostly within Occupational Activity Centers. Other main actor in Slovenia in the field of life long education for persons with intellectual disabilities are NGOs, most known is the Slovenian association for persons with intellectual disabilities (Zveza Sožitje), a partner in this project, which connects 51 local societies (Društvo Sožitje) all over Slovenia and Special Olympics Slovenia.

#### **2.4 Programs of lifelong learning for persons with intellectual disabilities offered by zveza sožitje and occupational activity centers**

Zveza Sožitje offers different programs of lifelong learning for persons with intellectual disabilities. Training for independent, active life and work of persons with intellectual disabilities includes learning on how one takes care of him/herself, seminar for girls and boys, self-advocacy, experience camps. Program is set in a way that teaches persons with intellectual disabilities how to take care of themselves, how to take decisions on certain matters by themselves, how to self-advocate themselves, how to become aware of their rights and duties as grown up persons. The goal of the program is to equally include persons with intellectual disabilities in everyday life and to recognize their right on making decisions about themselves and as well obligations that come from these rights (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Within the program they as well offer computer training, camping – living in nature, experiential camps on the seaside, sport camps, art camps etc. They offer workshops, seminars or experiential camps where the participants gain new knowledge or straighten their already existing knowledge and skills. These are important for their equal participation in everyday life and work. On experiential camps, individuals gain skills how to actively spend their free time, take care of their physical condition and because of the locations and special circumstances of the camps, the participants are forced to communicate among them and jointly decide on activities.

Part of the program is also Abilimpiada Slovenia and MATP – Motor Activities Training Program. Abilimpiada is an olympiad in skills, habits, working abilities and socialization of people. It is an event of a competitive character that links people with disabilities of all categories, including people with intellectual disabilities. Competitors compete in categories of employment and leisure activities in which they present their creativity, knowledge and competences. MATP is a program for keeping or developing motoric skills of persons with greater scale of intellectual disabilities.

Attending these programs helps persons with intellectual disabilities to get to know their capabilities, raise their self-esteem and self-confidence. By independent attendance on seminars and workshops 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 programs offered by Zveza Sožitje are informative and publishing activities. They publish different printed materials with which they inform users – persons with intellectual disabilities and their parents, about the newest researches in the field of how to improve the quality of life. There is often a lack of access to information for adult persons with intellectual disabilities since information have to be understandable and adjusted to them. Because of that they are less included in education processes and that is why the informative and publishing activity is an important aspect of lifelong learning for adults with intellectual disabilities (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Zveza Sožitje conducts sport activities for persons with intellectual disabilities through a NGO called Specialna olimpijada Slovenije (Special Olympics Slovenia). The result of this idea is the preservation of psychophysical abilities and socialization of people with intellectual disabilities. The slogan of the Special Olympics is: "Let me win, but if I can not win, let me be brave in my attempt." Encouraging cultural activities; Zveza Sožitje enables persons with intellectual disabilities to present artworks and the results of their year-round efforts in the field of culture. When presenting their own achievements and abilities at organized cultural events, persons with intellectual disabilities confirm their own quality of their work and creativity.

Zveza Sožitje on national level offers as well training and education for families of persons with intellectual disabilities.

Programs of lifelong learning of local societies Društvo Sožitje are diverse. They depend on material, space capabilities, human resources – individuals that conduct activities in local societies are mostly volunteers. They offer programs like computer workshops, workshops for strengthening reading and writing, English classes, dance schools, swimming classes, learning social skills, workshops for making different products from different materials, programs for healthy lifestyle, first aid workshops, cooking workshops, excursions, activities for including in the local community, etc. (Jordan Simončič, 2012; Zveza Sožitje n.d.).

Programs of lifelong learning that are conducted in an Occupational Activity Centers are written in their annual plans and they are conducted according to the interest of individuals and their capabilities. Interviews with the person with intellectual disabilities and their mentors are first conducted, to determine their

wishes and capabilities, and according to this, an individual plan is prepared for them. It depends on the Occupational Activity Center to what extent this programs are conducted. Some Occupational Activity Centers are more work orientated, they teach persons with intellectual disabilities how to conduct certain working processes, teach them skills how to make products for example sawing, and carton gluing. They are more and more aware of the importance of lifelong learning for persons with intellectual disabilities and they pay attention to these aspects as well. They provide contents for gaining 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 speak about subjects like relationships, love, have cooking workshops, dance classes, reading classes, etc. (Jordan Simončič, 2012).

Since the population is aging, the occupancy of Occupational Activity Centers is at its full capacity and there are waiting lists for the persons with intellectual disabilities to get included. The government did not adjust on time to this demographical change and we are currently facing a problem in Slovenia - persons with intellectual disabilities have to stay at home after they finish their schooling until an open spots comes up in an Occupational Activity Centers. This means that they are being excluded from the lifelong learning and educational process. Lifelong learning process in their home environment represents a good solution so that the persons with intellectual disabilities do not stop with their learning process.

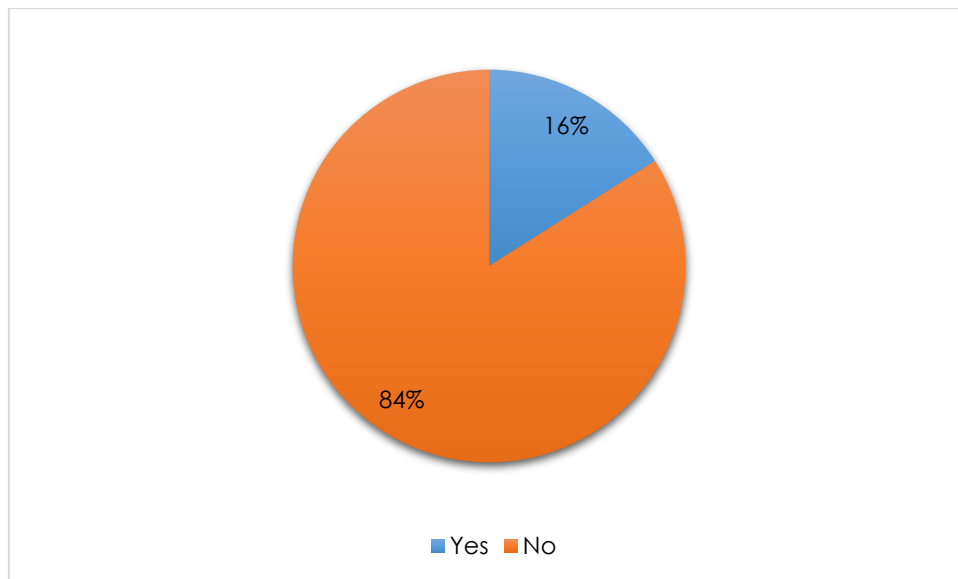
## **2.5 Questionnaire analysis**

25 families with AFMID filled out questionnaire.

### **Part 1: General information about the family**

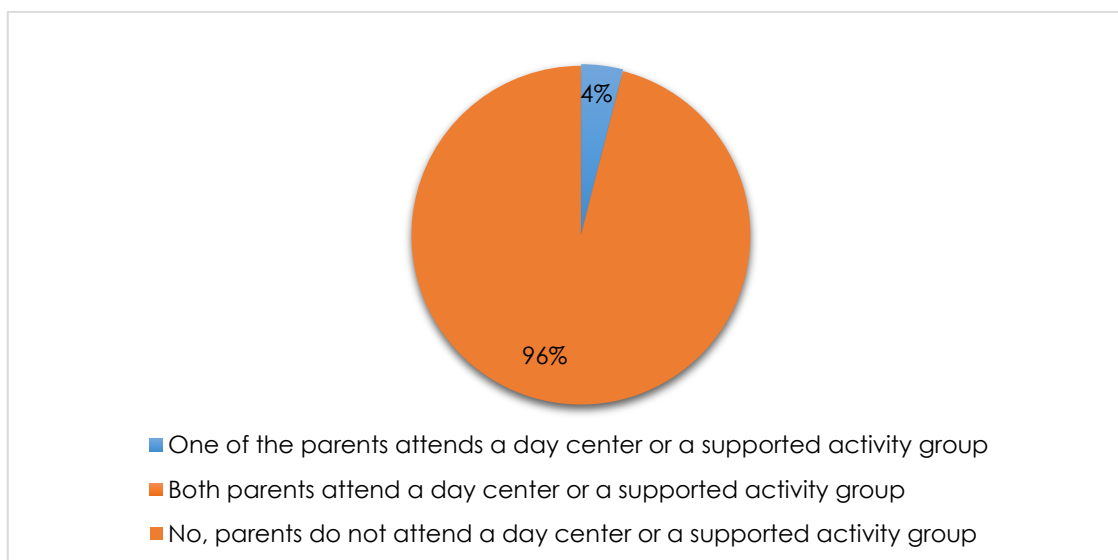
**Age of parents and AFMID:** the age of AFMID that participated in the questionnaire was between 16 and 60, their average age is approximately 32 years. The age of the parents was between 36 and 78, their average age is approximately 55 years.

**Are there any other children with intellectual disabilities in the family?**



The majority of families (84 % e.g. 21 families) has just one children with intellectual disabilities while in 16 % (4 families), families have more then one children with intellectual disabilities.

**Do either of the parents attend an Occupational Activity Centers or a supported activity group (as a participant)?**

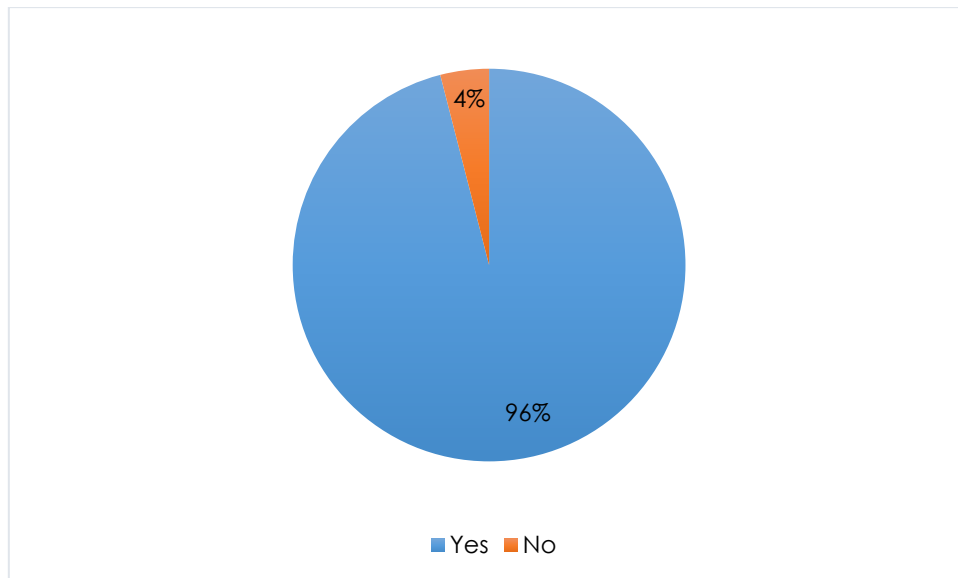


In majority of families 96 % (24 families), parents do not attend an Occupational Activity Center or supported activity group. In 4 % (1 family) of the families, one of the parents attends an Occupational Activity Center and there are no families where both parents would attend an Occupational Activity Center.



## Part 2: questions for the whole family

### Q1: Does the person with intellectual disabilities live at home?



In majority of families 96 % (24 families) AFMID lives at home.

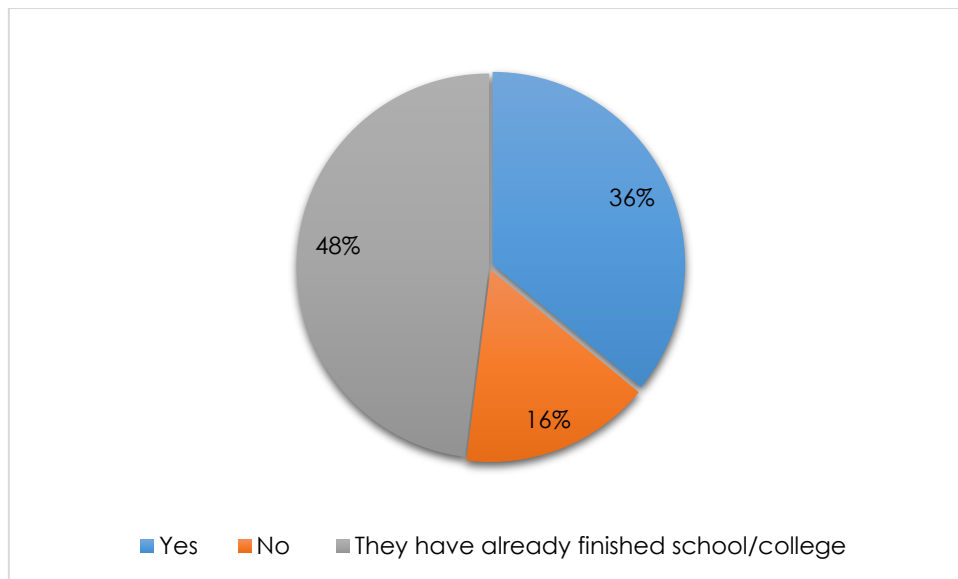
### Q2: Does the person with intellectual disabilities live in a shared house or supported living?



In 4 % (1 family) of the cases, AFMID lives in a shared house or supported living.

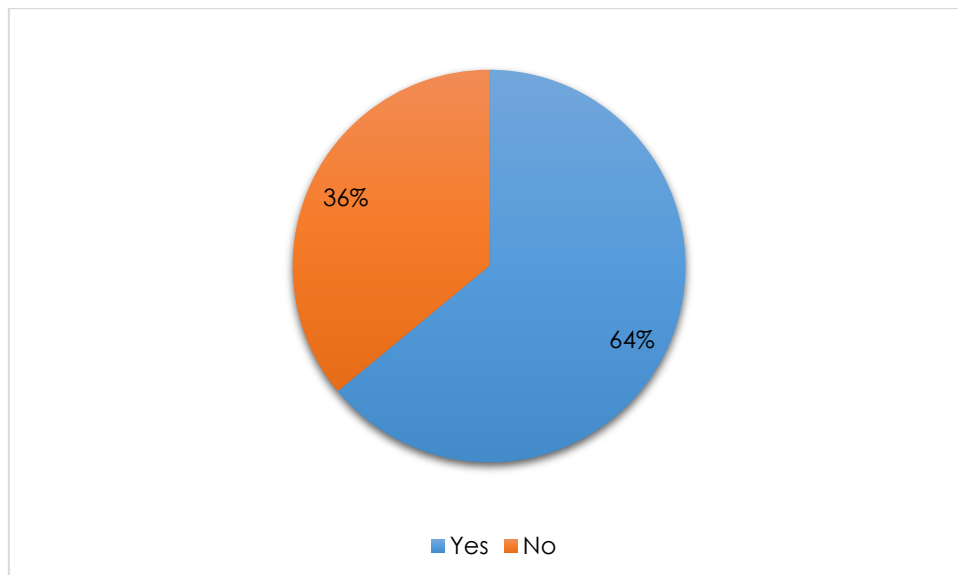
### Q3: Does the person with intellectual disabilities go to school or college?





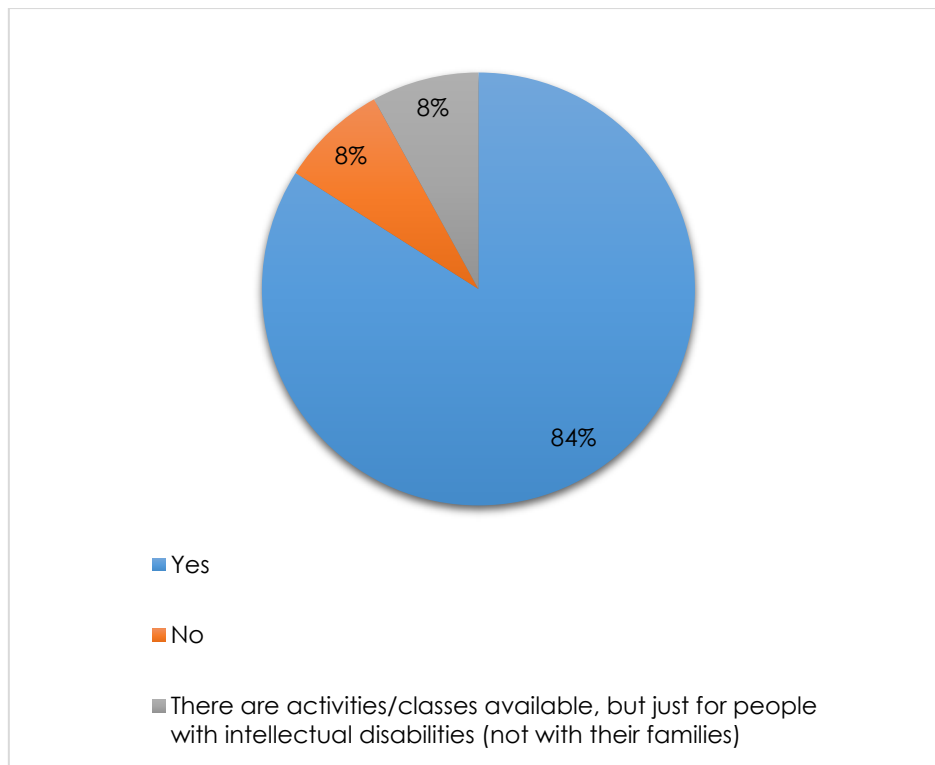
48 % (12 AFMID) have already finished school, 36 % (9 AFMID) are still in school and 16 % (4 AFMID) percentage of AFMID are not in school.

**Q4: Does the person with intellectual disabilities go to an Occupational Activity Centers or activity group?**



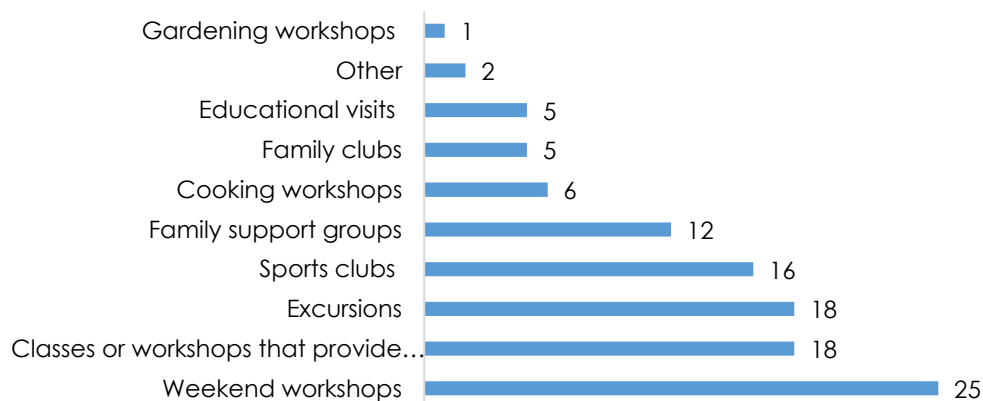
64 % of AFMID (16 persons) go to an Occupational Activity Center or activity group and 36 % (9 persons) are not included in an Occupational Activity Center.

**Q5: Are there opportunities close to your home for the person with intellectual disability to go to activities/classes with their family?**



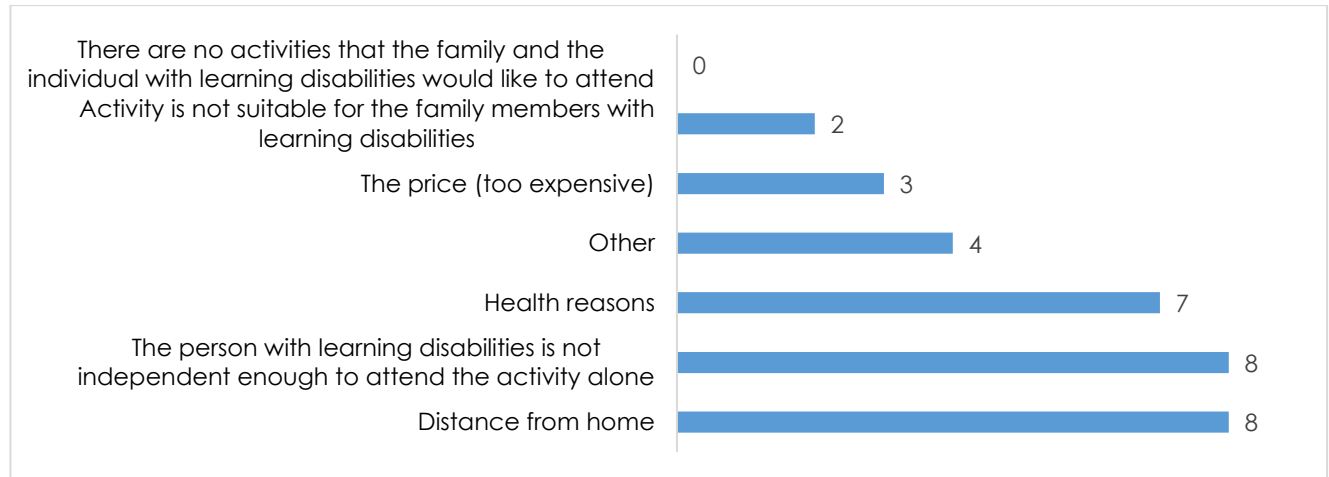
84 % of the interviewers (21 families) answered that there are opportunities close to their home to attend activities/classes together with AFMID. 8 % (2 families) answered that there are no activities available close to their home. 8 % (2 families) answered that there are activities available that just AFMID could attend.

#### Q6: Which activities/classes are available? (More than one answer possible.)



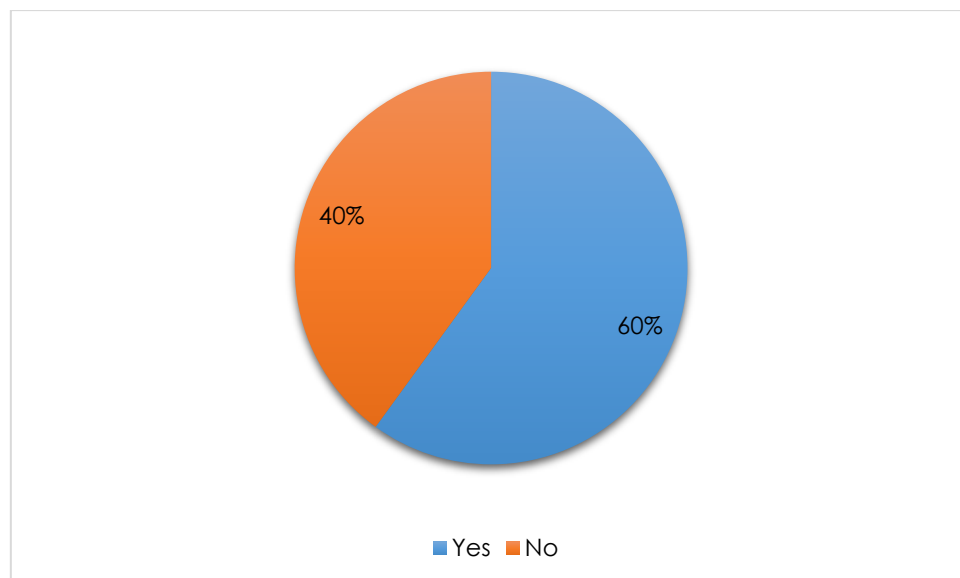
Most frequently answered option was weekend workshops (all 25 families answered this), following by classes or workshops that provide information on life skills (such as healthy living, legal rights, using money, etc.), excursions and sport activities. 6 families answered that cooking workshops are available to them and one of the family answered that they have available gardening workshops.

**Q7: If you do not attend activities, what is the reason? (More than one answer possible.)**



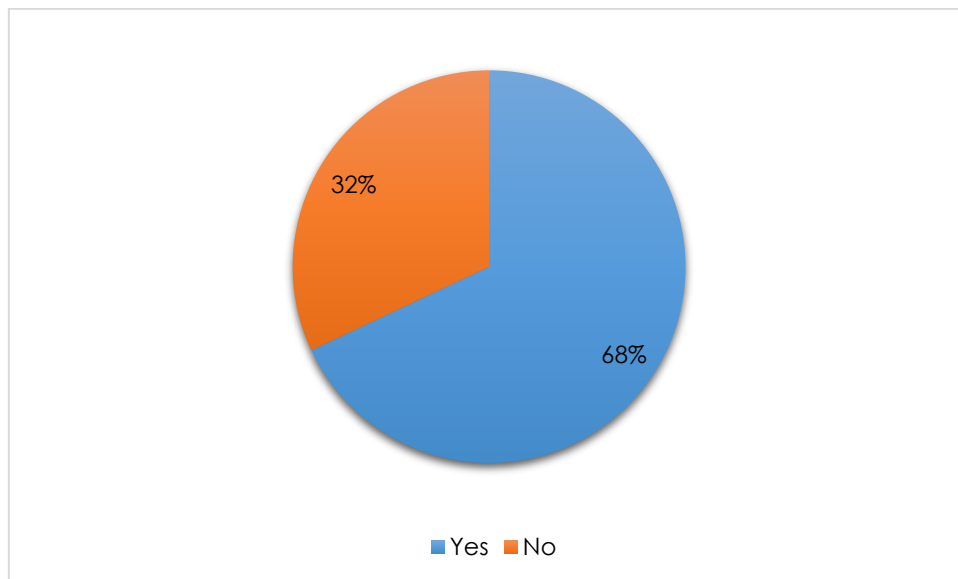
Most common answer to the question why the families do not attend activities was distance from home and the person with intellectual disabilities is not independent enough to attend the activity alone (8 out of 25 families stated that two reasons).

**Q8: Would you be interested in attending cooking workshops?**



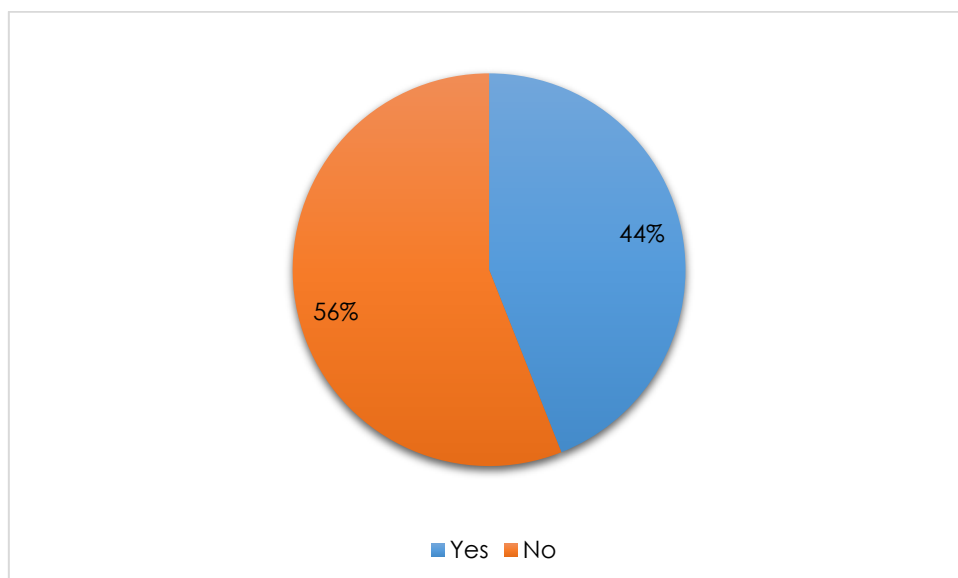
60 % (15 families) would attend cooking workshops, while 40 % (10 families) would not be interested in attending cooking workshops.

**Q9: Would you be interested in attending gardening workshops?**



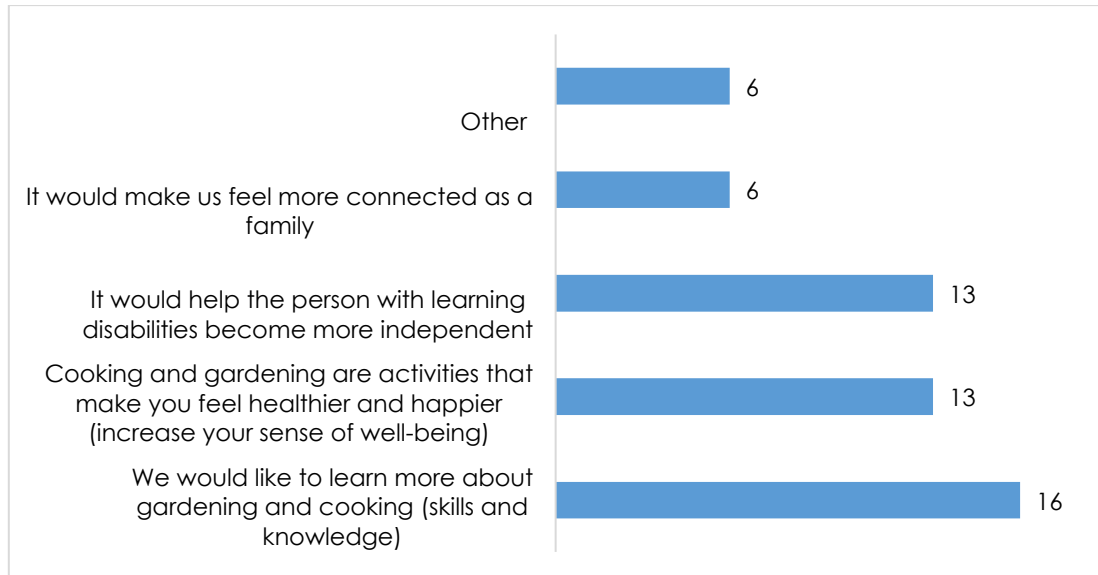
68 % of the families (17 families) would attend gardening workshops while 32 % of the families (8 families) would not attend this kind of workshops.

**Q10: Would the family (parents, brothers, sisters, etc.) be interested in attending cooking and gardening workshops together with the person with intellectual disability?**



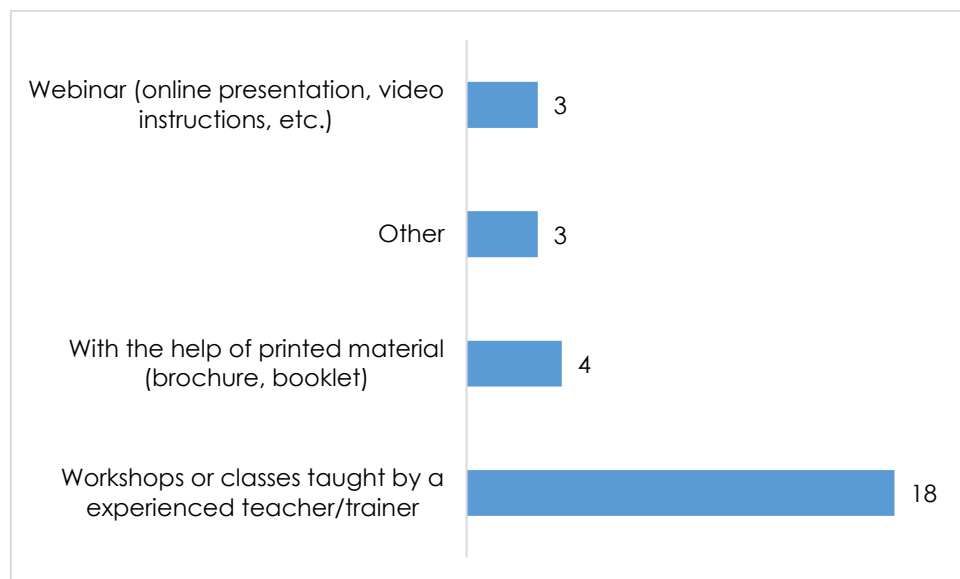
56 % of the families (14 families) answered that they would not attend workshops together with the AFMID, while 44 % (11 families) would attend the workshops together with AFMID.

**Q11: Why would you attend these kind of activities (cooking and gardening workshops)? (More than one answer possible.)**



16 families answered that they would attend cooking and gardening workshops to gain new skills and knowledge, 13 families answered that this activities provide you with better well-being and that it would help the person with intellectual disabilities to become more independent. 6 families answered that this would connect them more as a family and 6 families choose the answer other.

**Q12: How would you prefer to learn more about cooking and gardening? (More than one answer possible.)**



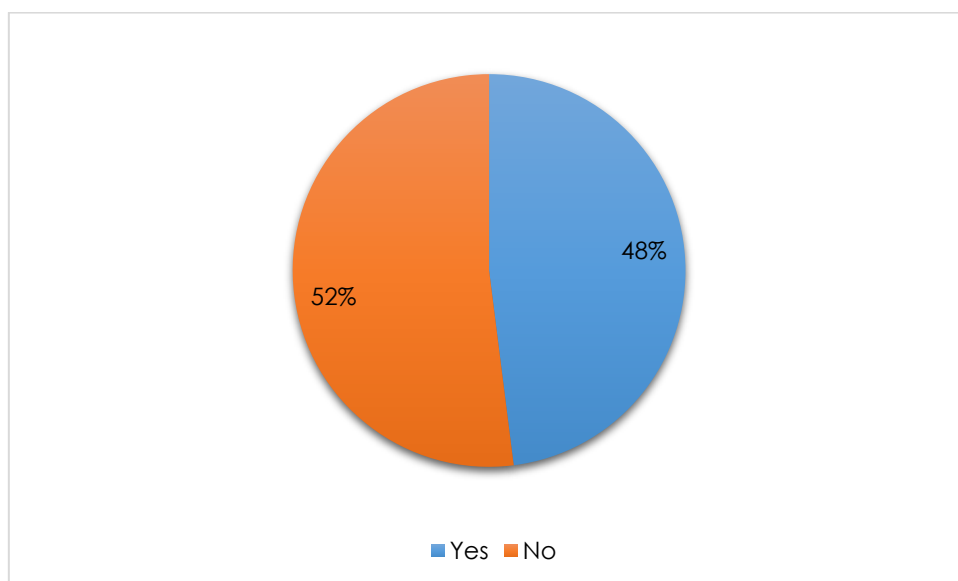
The majority (18 families) answered that they would like to learn about cooking and gardening in workshops or classes taught by an experienced trainer.

### PART 3: QUESTIONS FOR ADULT FAMILY MEMBERS WITH INTELLECTUAL DISABILITIES

#### Q1: What is your favorite meal? (open question)

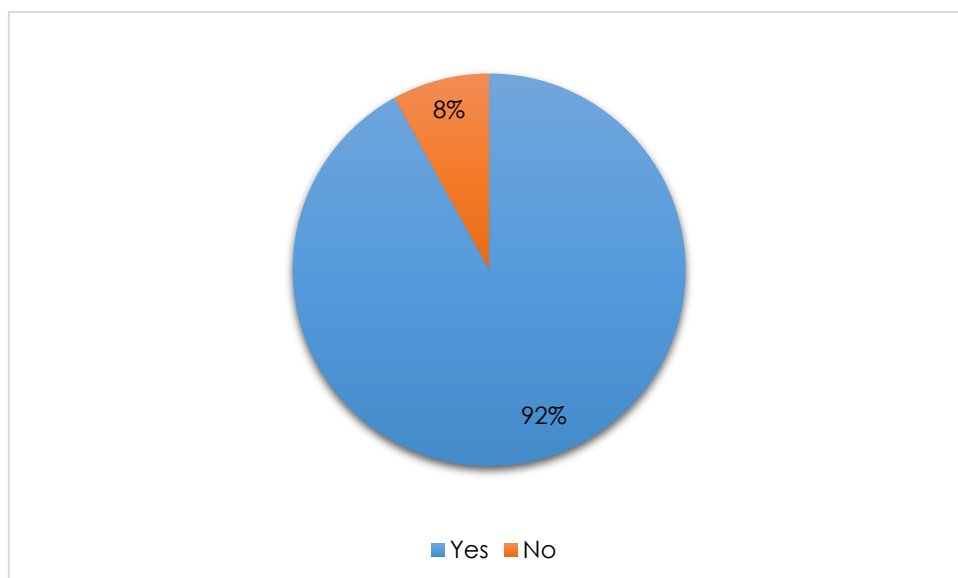
Common answers were: toast, pizza, spaghetti, lasagna, gnocchi, soup, steak, pancakes, cheese, salami, broccoli and some other simple meals.

#### Q2: Can you make or cook it yourself?



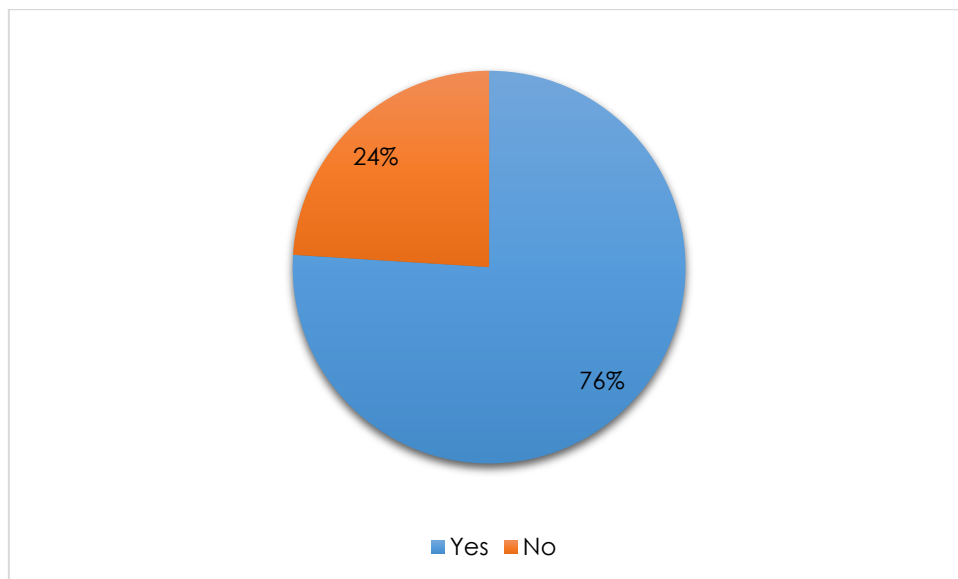
52 % (13 AFMID) answered that they do not know how to cook their favorite dish while 48 % (12 AFMID) answered they can cook their favorite meal.

#### Q3: Would you make or cook it at home if you knew how to?



92 % of AFMID (23 persons) answered they would make or cook the meal if they would know how, and just 8 % (2 AFMID) answered he/she would not prepare it on his/her own.

**Q4: Would you like to grow your own fruit or vegetables for the meal? (plant the seeds, look after the plants as they grow and harvest the fruit or vegetables).**



76 % of AFMID (19) would like to grow their own fruit or vegetables for the meal, while just 24 % (6 AFMID) would not like to grow it on their own.

## 2.6 Questionnaire summary

According to the results, majority of AFMID that participated in the questionnaires live at home and majority visits an Occupational Activity Center or activity group. Majority of the families and AFMID have opportunities to attend activities close to their home, mostly sport activities and different (weekend) workshops. The most frequently stated reason why the families do not attend activities was, the distance from home, following health reasons. This confirms our assumptions that bringing education closer to home would be a good solution for the families to attend lifelong educational processes.

Most of the families and AFMID would be interested in gardening and cooking activities but the majority of the parents would not attend the workshops with their AFMID.

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

wish 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 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 families 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 l. 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 favour 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 re-education 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 pre-training 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.

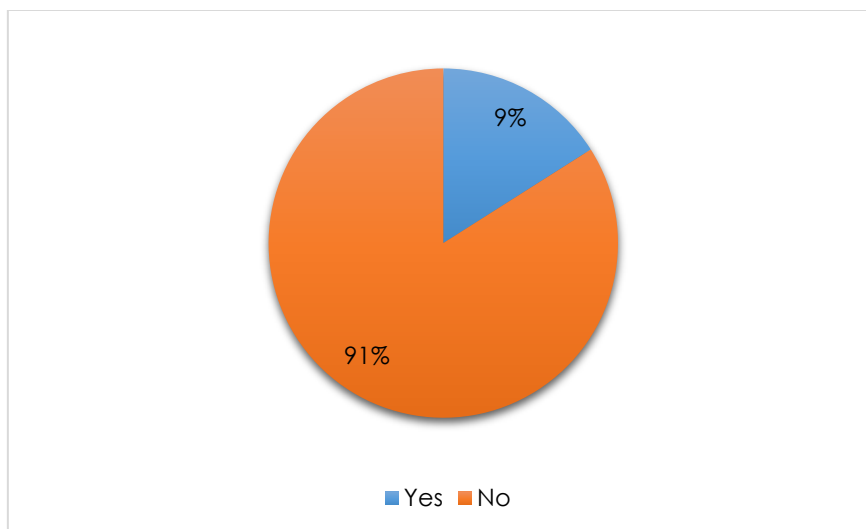
### 3.5 Questionnaires analysis

Questionnaire was filled out by 22 families with AFMID.

#### PART 1: GENERAL INFORMATION ABOUT THE FAMILY

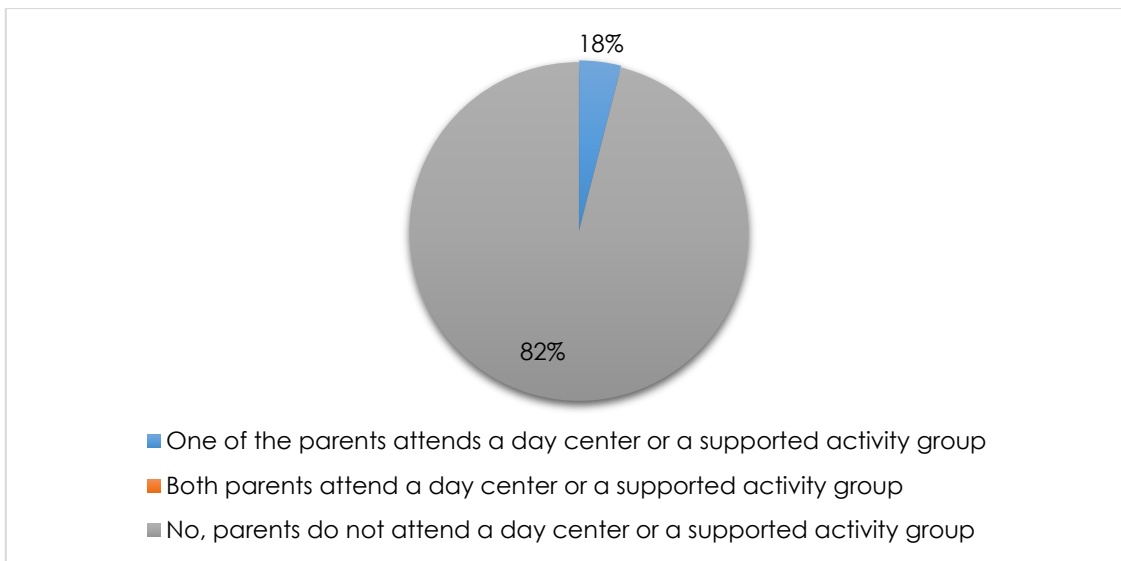
**Age of parents and AFMID:** the age of AFMID that participated in the questionnaire was between 18 and 81, their average age is approximately 49,5 years. The age of parent 1 was between 52 and 92, their average age is approximately 64 years, the age of the second parent is between 54 and 88, their average age is approximately 64,5 year.

#### Are there any other people with intellectual disabilities in the family?



The majority of families (91 % e.g. 20 families) has just one children with intellectual disabilities while in 9 % (2 families), families have more than one children with intellectual disabilities, specifically on person with Down Syndrome and one person with chronic depression.

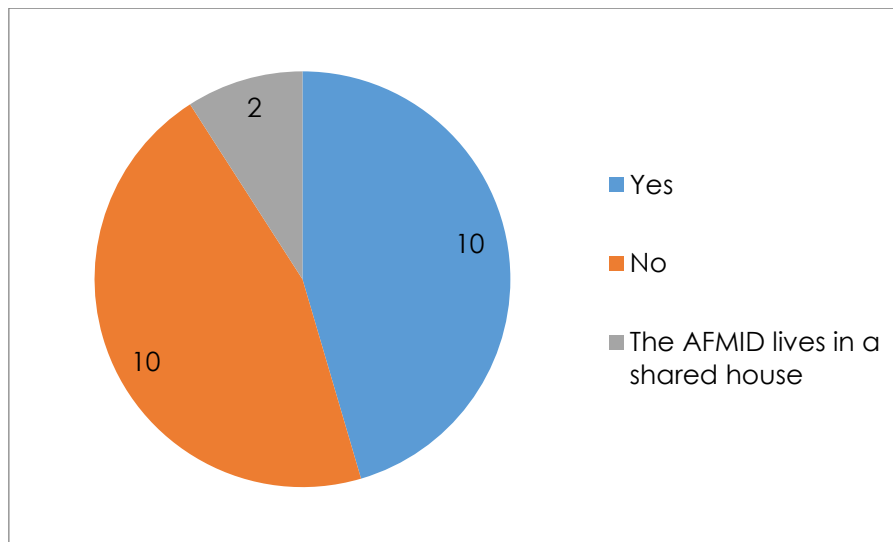
**Do either of the parents attend a day centre or a supported activity group (as a participant)?**



In majority of families 82% (18 families), parents do not attend a day centre or supported activity group. In 18% (4 families) of the families, one of the parents attends a day centre and 0% of the families have both parents attending a day centre.

## PART 2: QUESTIONS FOR THE WHOLE FAMILY

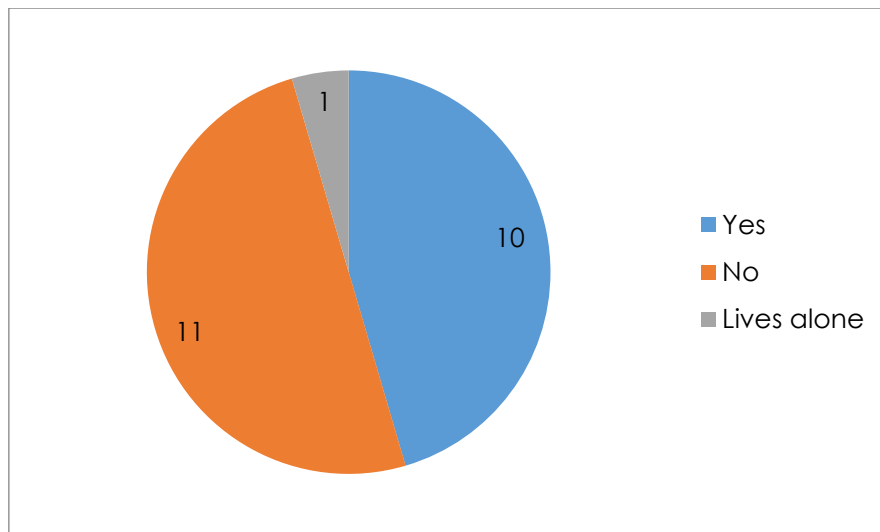
### Q1: Does the person with intellectual disabilities live at home?



In the 46 % of families, the AFMID lives at home, in the 45% of the families, the AFMID is not living with the families. The 9% answered that the AFMID is living in a shared house with other people with intellectual disabilities.

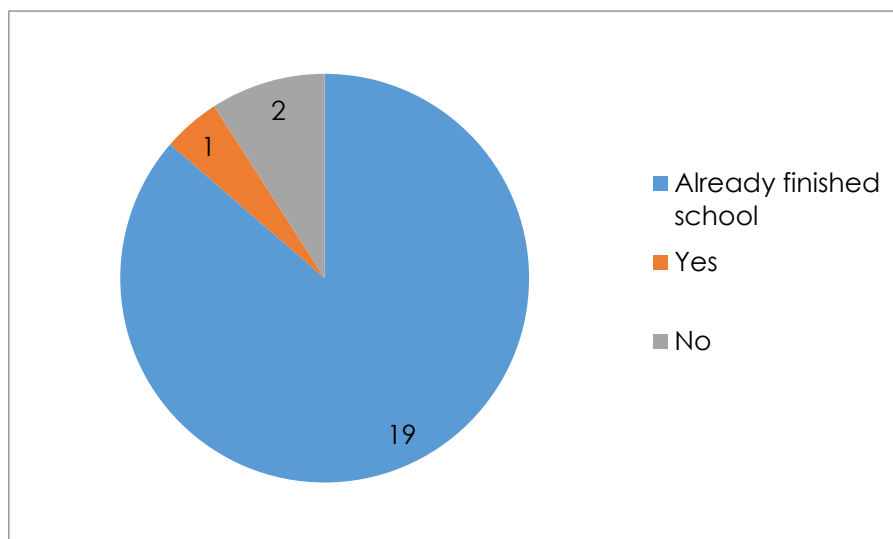
### Q2: Does the person with intellectual disabilities live in a shared house or supported living?





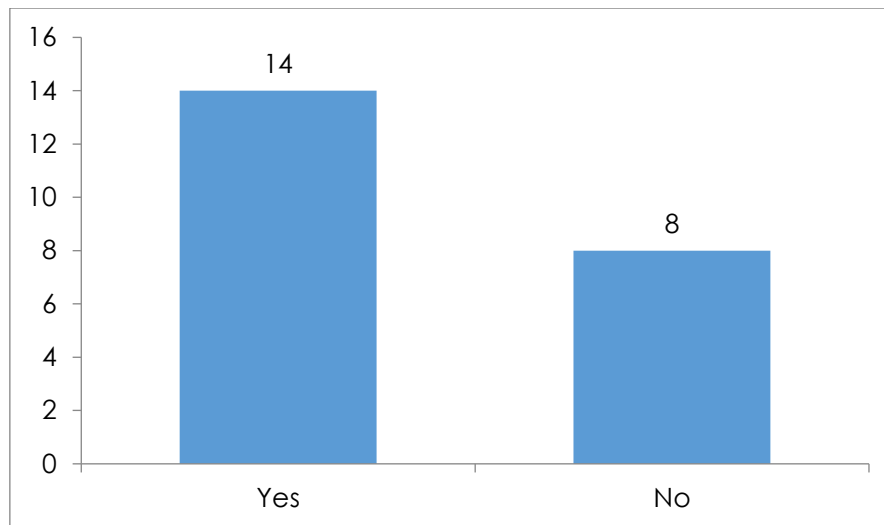
In 11 cases (50 % of the total of the respondents), the AFMID does not live in a shared house or supported living. In 10 cases (45,5%), the AFMID lives in a shared house or supported living. One respondent (5,5%) said the AFMID lives alone in a house adapted to his exigencies.

**Q3: Does the person with intellectual disabilities go to school or college?**



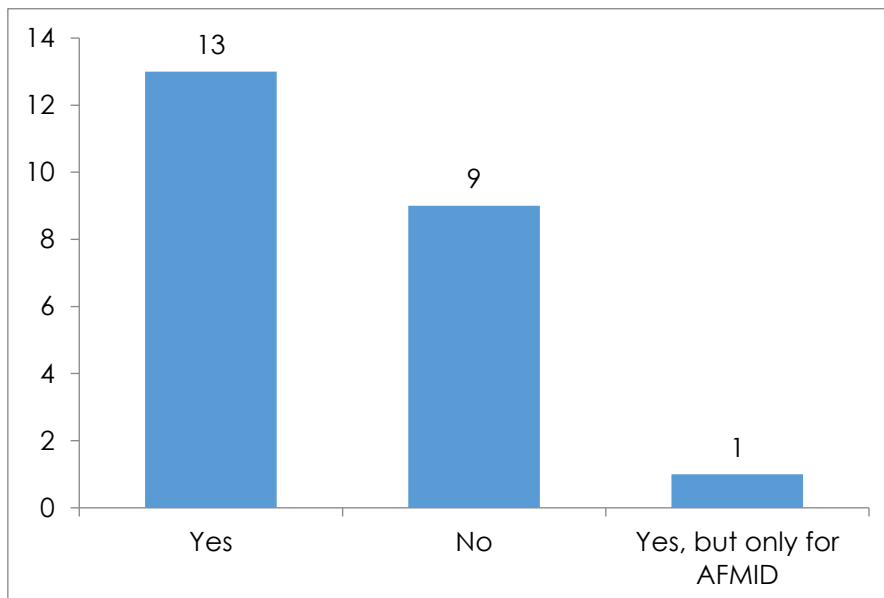
86 % (19 AFMID) have already finished school, 5 % (1 AFMID) are still in school and 9 % (2 AFMID) percentage of AFMID are not in school.

**Q4: Does the person with intellectual disabilities go to any kind of day centre or activity group?**



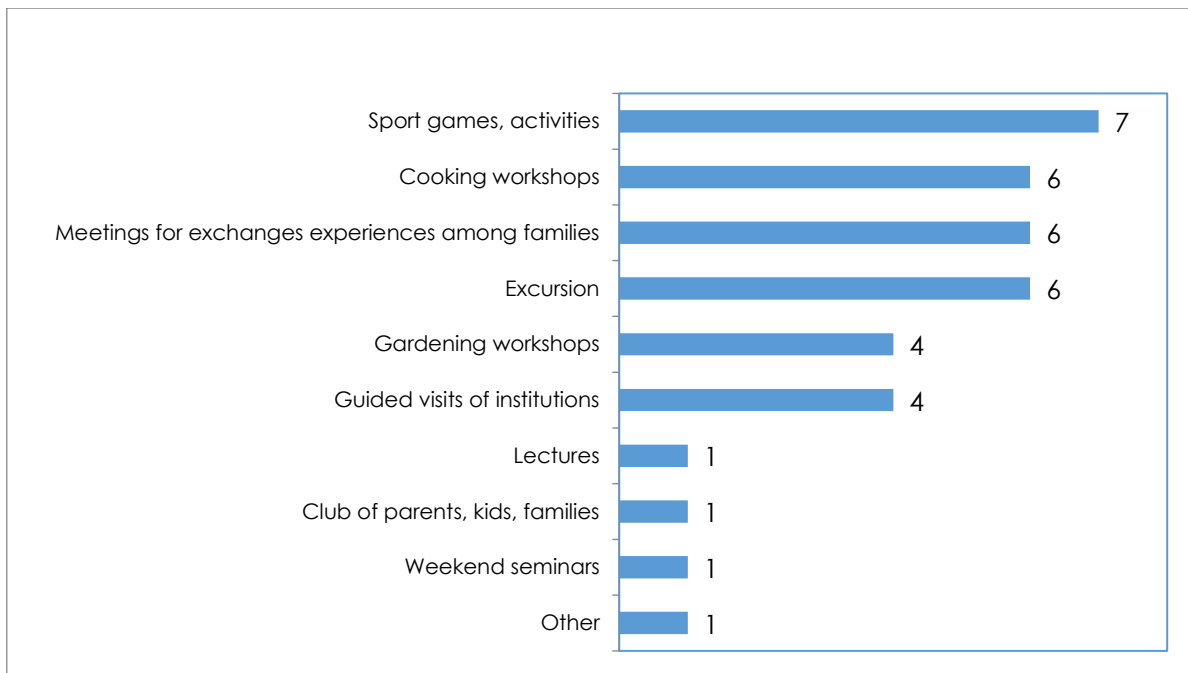
64 % of AFMID (14 persons) go to a day centre or activity group and 36 % (8 persons) are not included in a day centre.

**Q5: Are there opportunities close to your home for the person with intellectual disability to go to activities/classes with their family?**



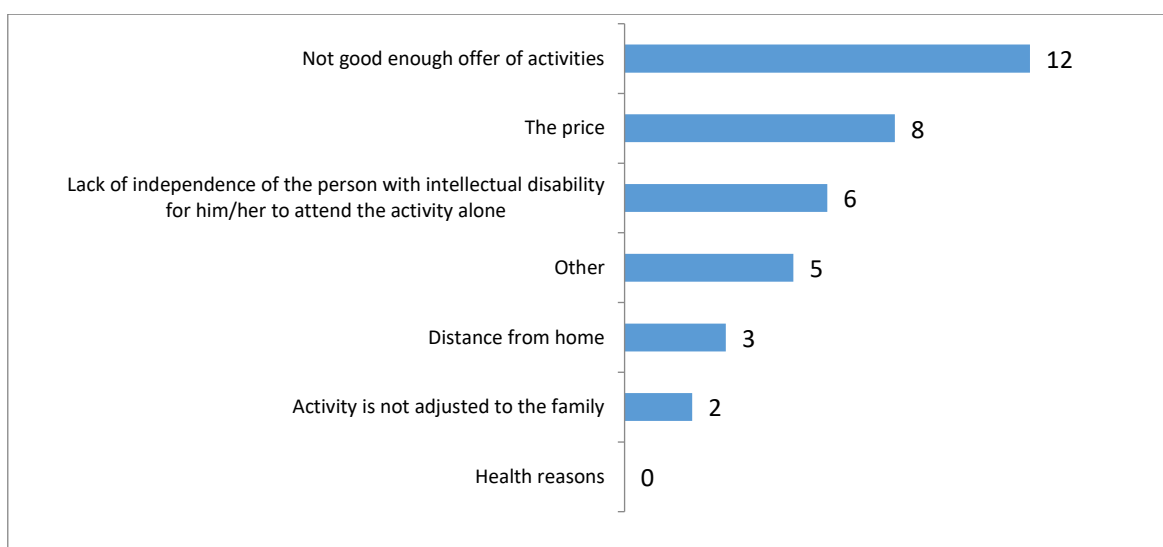
57% of the interviewers (13 families) answered that there are opportunities close to their home to attend activities/classes together with AFMID. 39% (9 families) answered that there are no activities available close to their home. 4 % (1 families) answered that there are activities available just for the AFMID.

**Q6: Which activities/classes are available? (More than one answer possible.)**



Most frequently answered options were sports games and connected activities (7 families answered this), followed by excursions, cooking workshops and meetings for exchanges experiences among families with AFMID. 4 families answered that gardening workshops and guided visits organised by institutions are available to them and one of the family answered that they have available gardening workshops.

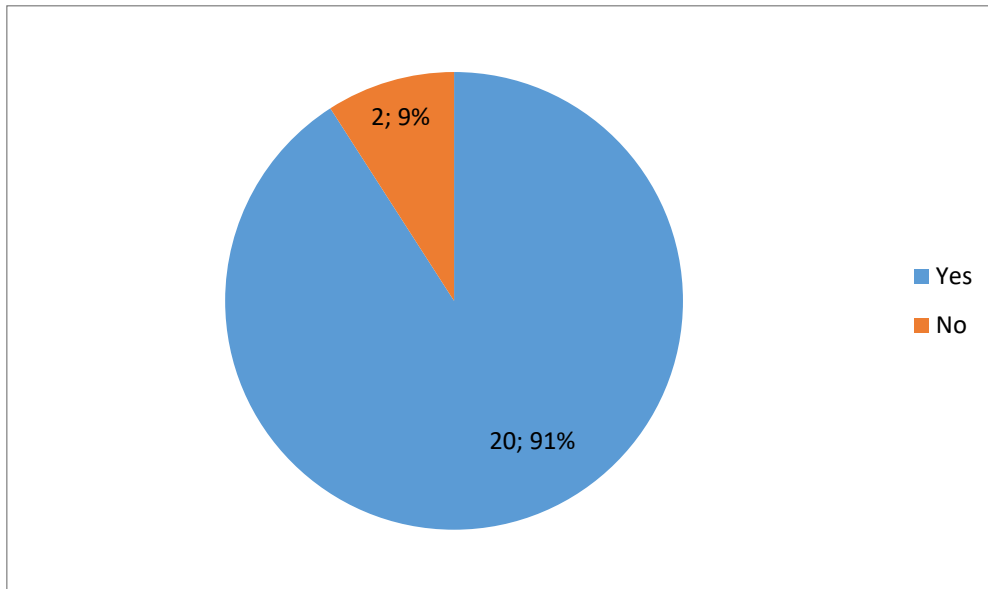
**Q7: If you do not attend activities, what is the reason? (More than one answer possible.)**



Most common answer to the question why the families do not attend activities was that the offer for the family is not good enough (12 families), followed by the price of the activities (8 families), 6 families answered "Lack of independence of

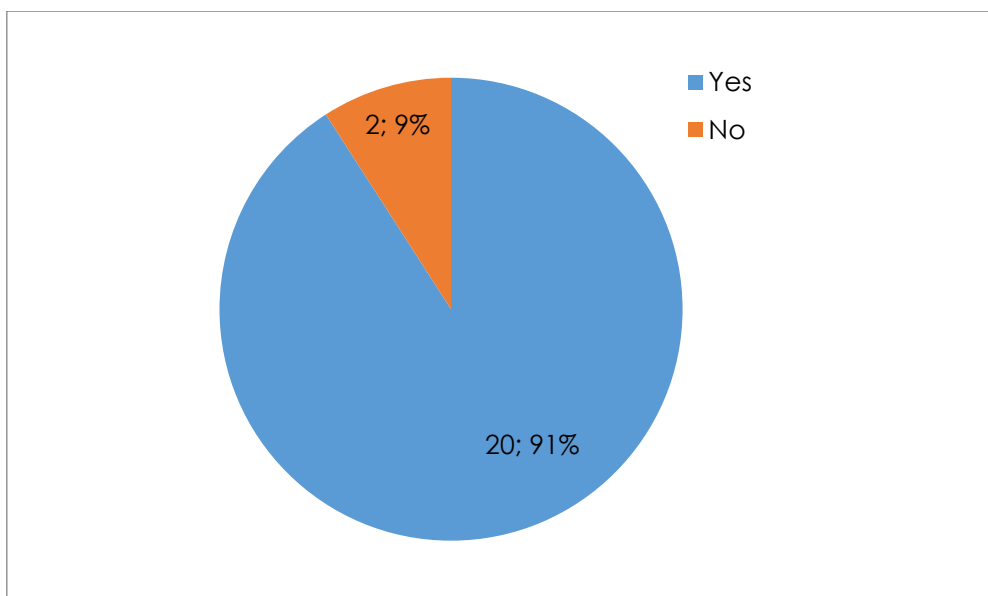
the person with intellectual disability for him/her to attend the activity alone". Distance from home was checked only by 3 families.

**Q8: Would you be interested in attending cooking workshops?**



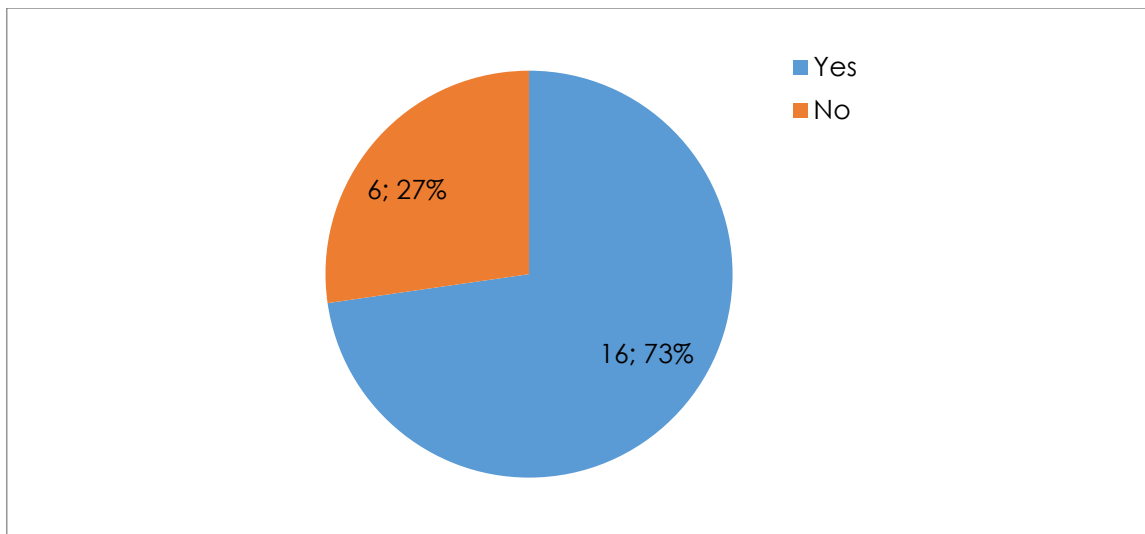
91% (20 families) would attend cooking workshops, while 9% (2 families) would not be interested in attending cooking workshops.

**Q9: Would you be interested in attending gardening workshops?**



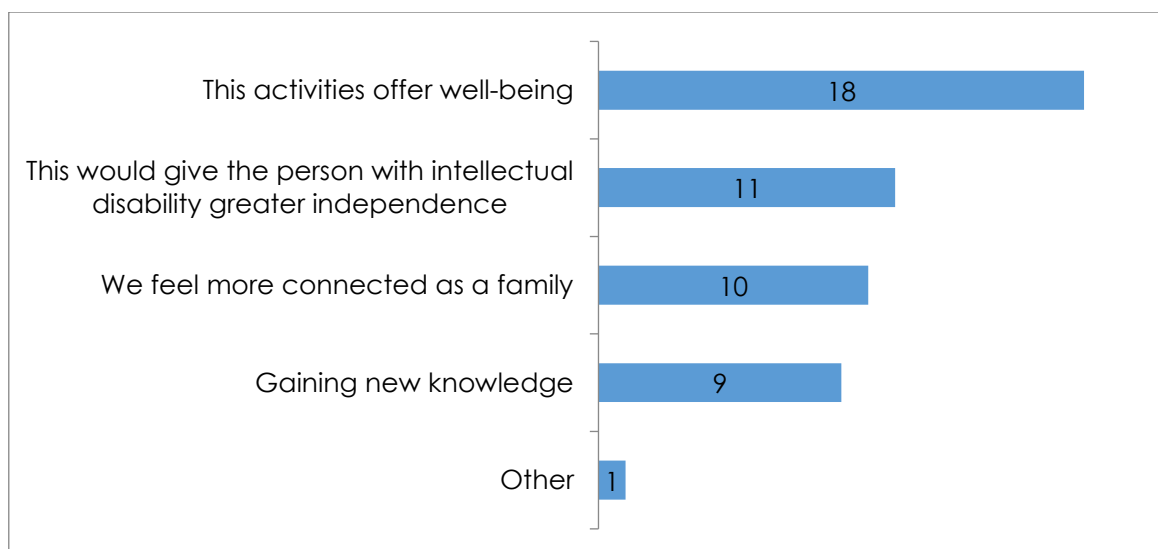
91% (20 families) would attend cooking workshops, while 9% (2 families) would not be interested in attending cooking workshops.

**Q10: Would the family (parents, brothers, sisters, etc.) be interested in attending cooking and gardening workshops together with the person with learning disability?**



73% of the families (16 families) answered that they would attend workshops together with the AFMID, 27 44 % (6 families) would not attend the workshops together with AFMID.

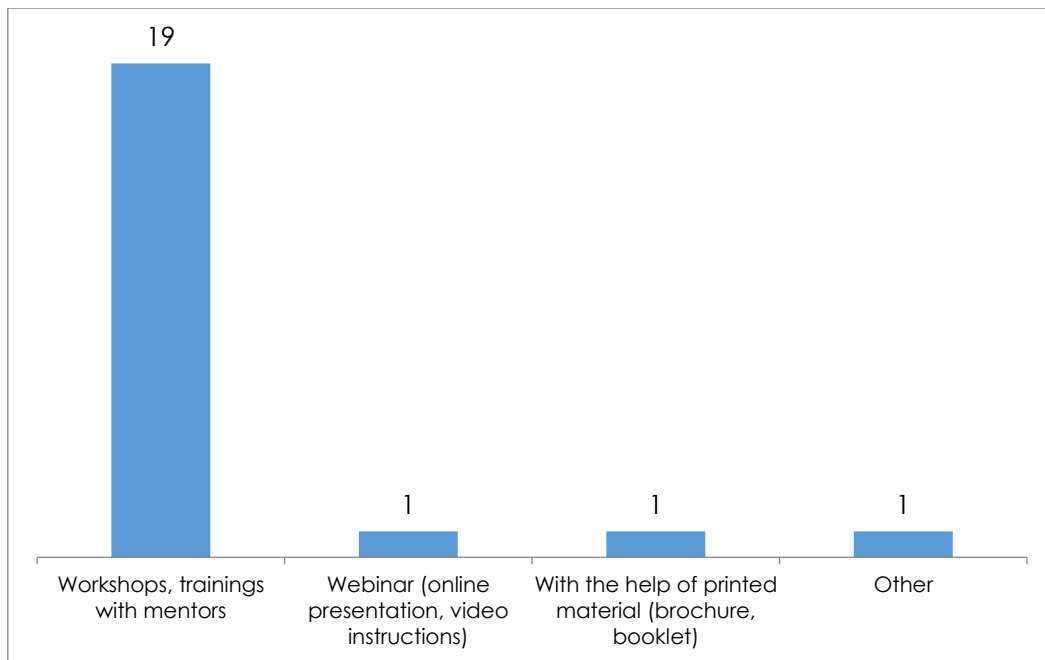
**Q11: Why would you attend these kind of activities (cooking and gardening workshops)? (More than one answer possible.)**



18 families answered that they would attend cooking and gardening workshops because these activities offer well-being, 11 families answered that they would give the person with intellectual disability greater independence,

10 families answered that these activities would connect them more as a family, 9 families answered that it is important for gaining new knowledge.

**Q12: How would you prefer to learn more about cooking and gardening? (More than one answer possible.)**



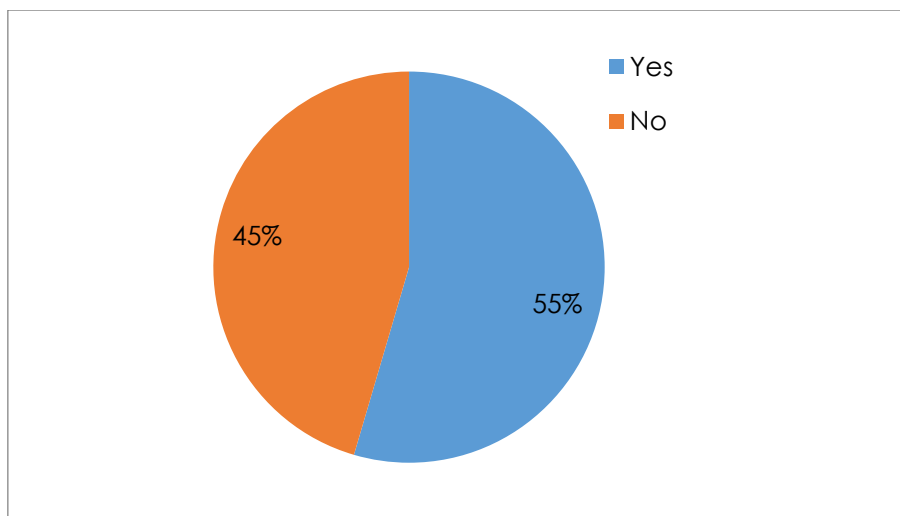
The majority (19 families) answered that they would like to learn about cooking and gardening in workshops or classes taught by an experienced trainer. One family selected the webinar, as well as printed materials and other ways (practical experience).

### **PART 3: QUESTIONS FOR ADULT FAMILY MEMBERS WITH INTELLECTUAL DISABILITIES**

#### **Q1: What is your favourite meal? (open question)**

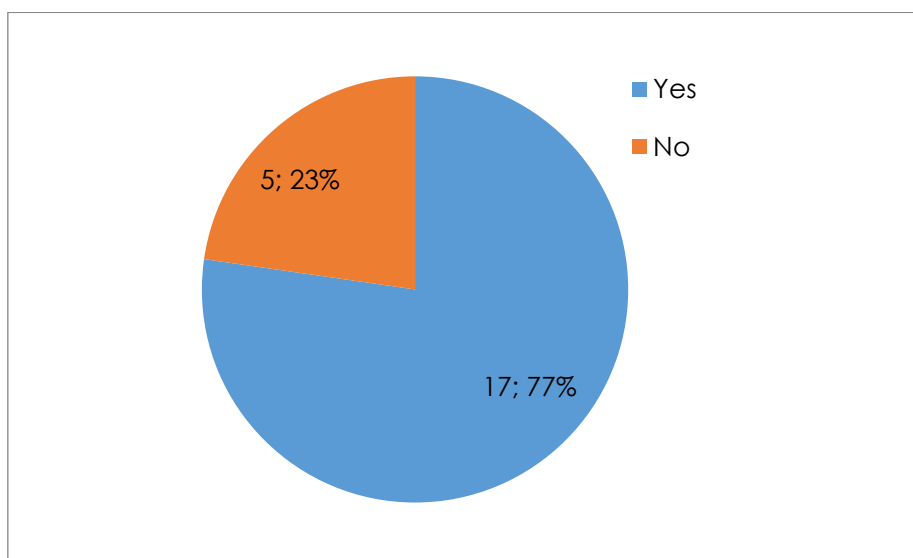
Common answers were: pasta with salmon, saffron risotto, baked potatoes, rice and chicken, pizza, chicken with potatoes, meat with baked potatoes, chocolate sweets, stew, desserts in general, baked pasta, lasagna.

#### **Q2: Can you make or cook it yourself?**



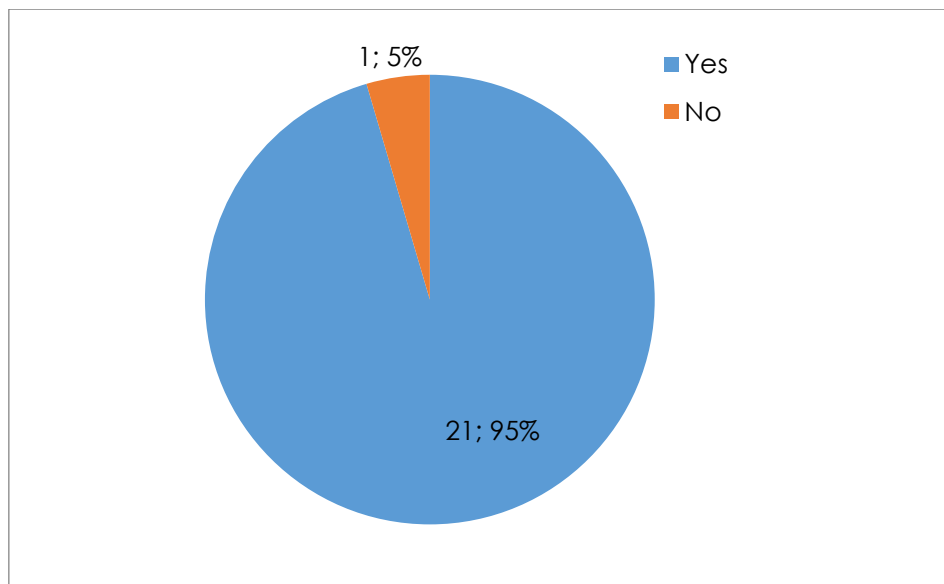
55 % (12 AFMID) answered that they know how to cook their favourite dish while 45 % (10 AFMID) answered they cannot cook their favourite meal.

**Q3: Would you make or cook it at home if you knew how to?**



77% of AFMID (17 persons) answered they would make or cook the meal if they would know how, and 23% (5 AFMID) answered he/she would not prepare it on his/her own.

**Q4: Would you like to grow your own fruit or vegetables for the meal? (plant the seeds, look after the plants as they grow and harvest the fruit or vegetables).**



95% of AFMID (21) would like to grow their own fruit or vegetables for the meal, while just 5% (1AFMID) would not like to grow it on their own.

### 3.6 Questionnaire summary

According to the results, half of the AFMID that participated in the questionnaires lives at home and the majority visits a day centre or activity group. The majority of the families and AFMID have opportunities to attend activities together, mostly sport activities, excursions and cooking workshops. The most frequently stated reason why the families do not attend activities was is connected with the lack of opportunities offer, following by the price of the activities. This suggests that it is desirable to widen the offer of activities with new activities so to provide better solutions for the families to attend lifelong educational processes.

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

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



### 3.7 References

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<https://www.disabili.com/lavoro/articoli-lavoro/formazione-e-opportunita-di-lavoro-per-persone-con-disabilita-in-16-regioni-italiane>

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## 4 NATIONAL REPORT 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.

The most important steps in the development of the adult education system are the Government's adoption of the Adult Education Strategy in November 2004, the establishment of the Adult Education Agency by the Government Decree in May 2006 and the adoption of the Adult Education Act in February 2007.

Adoption of the Adult Education Act establishes a normative framework and creates legal preconditions for further development of adult education as a full part of the overall educational system of the Republic of Croatia.

Today, adult education activities take place at the Agency for Vocational Education and Adult Education established by Agency for Vocational Education and Adult Education Act.

By the first article of the Adult Education Act, adult education in Croatia is defined as an overall adult learning process aimed at exercising the right to free personal development, employability training (gaining the first occupational qualifications, occupational retraining, acquisition and deepening of professional knowledge, skills and abilities) and training for active citizenship.

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.

In this context, there are more than 500 different institutions that run adult education programs in the Republic of Croatia.

Most of these institutions carry out adult education programs that meet the needs of the disadvantaged occupations or those that meet the needs of the most requested occupations in the labor market.

A very few of these institutions implement programs that acquire knowledge and skills in a very narrow and specific field of work.

Given that, over the last 20 years, especially in the last 10 years, the rights to live in a community and the decrease in social exclusion of persons with disabilities and the promotion of social innovations and their inclusion in society, as set out in the Europe 2020 Strategy Croatia, the United Nations Convention on the Rights of Persons with Disabilities and many other legal documents have been more intensively discussed, a need to develop adult education programs in the area of community social services for persons with intellectual and mental disabilities has emerged.

The area of lifelong learning for persons 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 persons with intellectual disabilities into regular education through the use of inclusive practices and is based on human rights.*

Throughout history the attitude towards the persons with intellectual disabilities in the Republic of Croatia has gone through the whole series of phases.

The main form of education for students with intellectual disabilities was traditionally education in special educational institutions which are special schools or special departments in which specialists educated children with intellectual 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, below the level of capabilities of those children, because of that, the potentials needed for successful integration, were not fulfilled.

Strong support for the integration of children with intellectual disabilities into the regular educational system was provided by the ideas of equal education and education for all, regardless of the existing differences on the basis of the 1948 Human Rights Declaration and 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.

Article 24, paragraph 1 of the Convention states:

»States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- Enabling persons with disabilities to participate effectively in a free society.«

Paragraphs 4 and 5 of the same Article states:

»In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.«

Based on the Convention, the National Strategy for equalization of opportunities for persons with disabilities from 2017 to 2020 was adopted and its goal is to progress and enhance the protection of the rights of persons with disabilities in order to make the Croatian society as sensitive and adapted to the necessary changes in favor of equalizing the opportunities of persons with disabilities, for which 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, prevent discrimination and the strengthen all forms of social solidarity.

The integration in the 60s and 70s of the last century became legally regulated in Western Europe and the World.

The Republic of Croatia has been supporting education integration process for more than 20 years.

The guidelines of education over the last two decades emphasize the principle of educational integration, which primarily refers to the inclusion of children with intellectual disabilities into a system of formal education.

More recently, the term educational inclusion or inclusion of everyone in education is more frequently used.

Inclusive education is a concept that expands and deepens the educational model of integration of children with intellectual disabilities into regular education.

Educational inclusion is not the same as educational integration. 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 make a continuous process in which the educational and living needs of children with special educational needs, including children with intellectual disabilities, will be met.

For a successful implementation of inclusion, the emphasis is on more actors (students, teachers, principals, professional associates and parents) and other factors (local government, other institutions in co-operation with the school, education policy of the country) that are not hierarchically placed, about in continuous cooperation.

Students with intellectual disabilities involved in a regular education system have support of teaching assistants, individualized programs, customized equipment and other necessary contents for quality learning.

According to the latest available data from the Croatian National Institute of Public Health in the Republic of Croatia, there are 511 850 persons with disabilities, out of which 307 934 are men (60%) and 203 916 are women (40%), and in this way persons with disabilities make up about 11.9% of the total population of the Republic of Croatia.

Of the above mentioned number of persons with disabilities, 24,669 (4,8%) of them are persons with intellectual disabilities, and 29,6% of persons with disabilities have multiple disabilities that contribute to the functional impairment of the person with disability.

Persons 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 persons with disabilities reside in an institution.

Intellectual disability with a 66% share of light intellectual disability is the most common specified cause that determines the need for an appropriate form of education and 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.).

The data of the Croatian Institute for Public Health shows that in the Karlovac County there are 15103 persons with disabilities, making up 11.72% of the total population of the county. Among those 15103 persons 8744 (57.90%) are male and 6359 (42.10%) are female. Special education includes 4.0% of them, and also involves persons with intellectual and multiple impairments.

- *Non-formal education of persons with intellectual disabilities is the result of everyday activities in the work environment, in the family or in the free time and usually does not end with the issuance of an official document.*

Throughout history persons with intellectual 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 until the middle of the twentieth century.

During the sixties of the last century there was a significant change in attitude towards disability and its interpretation - the medical model of disability gradually has changed into a social model.

Changing the way of understanding disability and introducing a social dimension into its definition also changes the goals of politics concerning persons with intellectual disabilities.

The main goal of the policy towards persons with intellectual disabilities is no longer the therapy and protection, but the full inclusion of persons with intellectual disabilities in society while exercising all their rights.

Under the influence of the mentioned social processes, emerges the policy of deinstitutionalization of persons with intellectual 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 intellectual 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.

A certain progress has been made in Croatia, especially through the process of inclusion that started in 1997 with the development of community-based housing services and establishment of Inclusion Promotion Association.

Community service centers, community-based housing support for people with intellectual disabilities and civil society organizations are increasingly establishing with support services made up of experts such as defectologists - rehabilitators, social workers, psychologists, doctors / nurses and other professionals, which are necessary for a lifelong learning to acquire skills for everyday life in the community.

The best example of that is the Center for rehabilitation "Ozalj", which acted as an institution where persons with intellectual disabilities were accommodated, but which, after the deinstitutionalization and transformation of the Center, has been changed into the Service Provider Center Ozalj, which provides numerous services related to the lifelong learning for easier and quality inclusion in the community.

However, these support services and organized 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 left alone in finding ways to learn the skills of everyday life activities.

This is an even bigger 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 have to invest more financial resources and separate more time.

It often happens that all attention of the family is directed to AFMID, and other members of the family are then feeling neglected.

All of that are the reasons why conducting education under guidance in environment in which families live and / or in their homes is required.

Through 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.

In order for persons with intellectual disabilities to be more independent, they need specific support. It means a lot to them when people who they love are with them, and for those who live in families these people are mostly parents, brothers and sisters.

Every person needs different type of help, occasional, limited, intensive or comprehensive. It is important that the provided support is of the highest quality and for that it is important that the people who provide that support (in AFMD homes those are parents and other family members) are educated and that they know how to approach and react in any situation so that they could apply the support to the person with intellectual disabilities as best as they can.

Inclusion of AFMD in everyday family activities gives a person a sense of personal value, allows her/him to express, develop her/his talents, independence and autonomy, establish common interests with other people, help preserve her/his health.

Every new experience is of great importance because it helps to develop individual lifestyles of all people, as well as AFMD.

- *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.*

Informal education is the oldest method of acquiring knowledge and skills. The main characteristics of informal education are:

- not organized from outside,
- there is no formal structure,
- the intensity of learning and time spent learning is decided by the person who is learning,
- derives from experience and situational challenges,
- is happening during everyday life and work.

Such type of learning can greatly help AFMD. The largest source of information here is the internet on which there are numerous e-platforms, web portals with



interesting learning contents, social networks among which some of them are suitable for easy and simple search.

Informal education encourages the development of the ability to find and choose information, and acquire "learning how to learn" competences based on new media and different life and / or work situations.

Interactive learning materials are already being used and developed and they are successfully raising the level of knowledge about the use of apps (on smartphones, tablets and computers), and the use of these same apps could improve the quality of life and independence.

Informal situations offer a specter of opportunities for acquiring knowledge.

For this reason, informal learning could be an important source of innovation in learning and teaching methods in the future.

Establishing a system of lifelong learning for families and their adult members with intellectual disabilities in the concept of bringing lifelong learning closer to their home ultimately depends on their interests and real 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**

20 families with AFMID filled out questionnaire.

#### **PART 1: GENERAL INFORMATION ABOUT THE FAMILY**

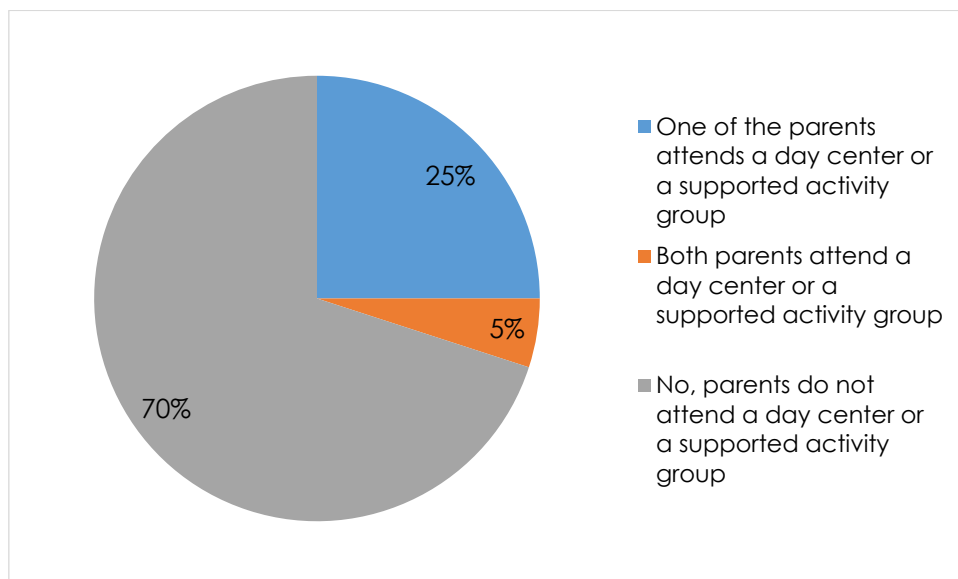
**Age of parents and AFMID:** the age of AFMID that participated in the questionnaire was between 20 and 43, their average age is 30.6 years. The age of the parents was between 45 and 72, their average age was 58 years.

**Are there any other children with intellectual disabilities in the family?**



All families (100 % e.g. 20 families) have only one child with intellectual disabilities.

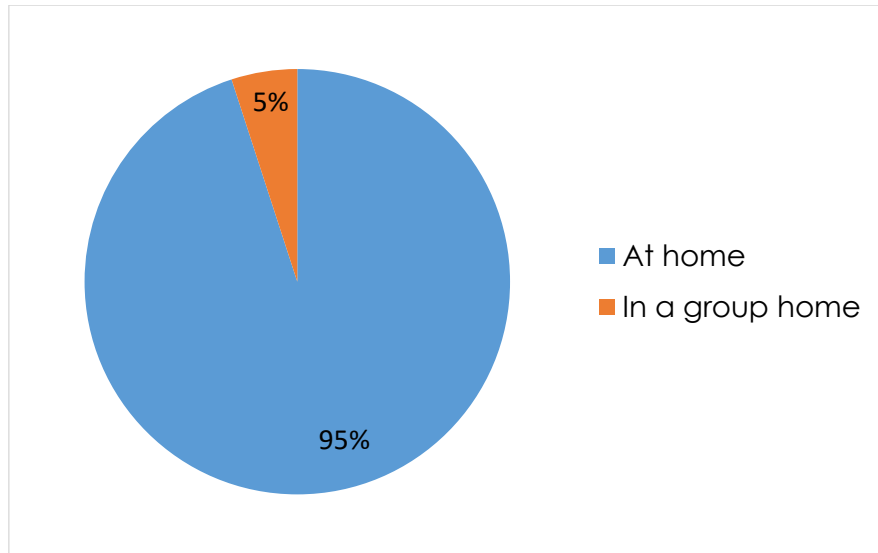
**Do either of the parents attend a day center or a supported activity group (as a participant)?**



In majority of families 70 % (14 families), parents do not attend a day center or supported activity group. In 25 % (5 families) of the families, one of the parents attends a day center and there is one family (5%) where both parents would attend a day center.

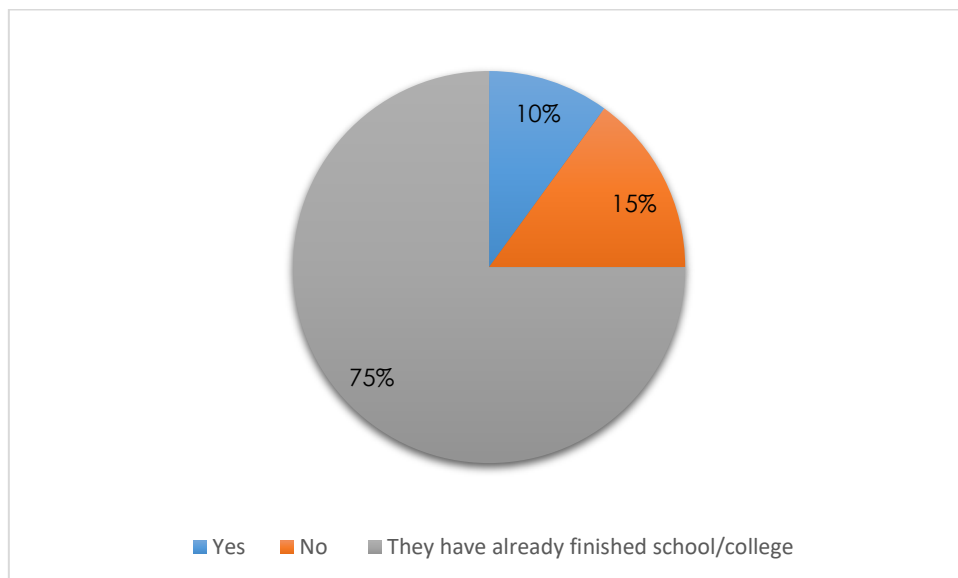
## PART 2: QUESTIONS FOR THE WHOLE FAMILY

**Q1& Q2: Does the person with intellectual disabilities live at home in a shared house or supported living?**



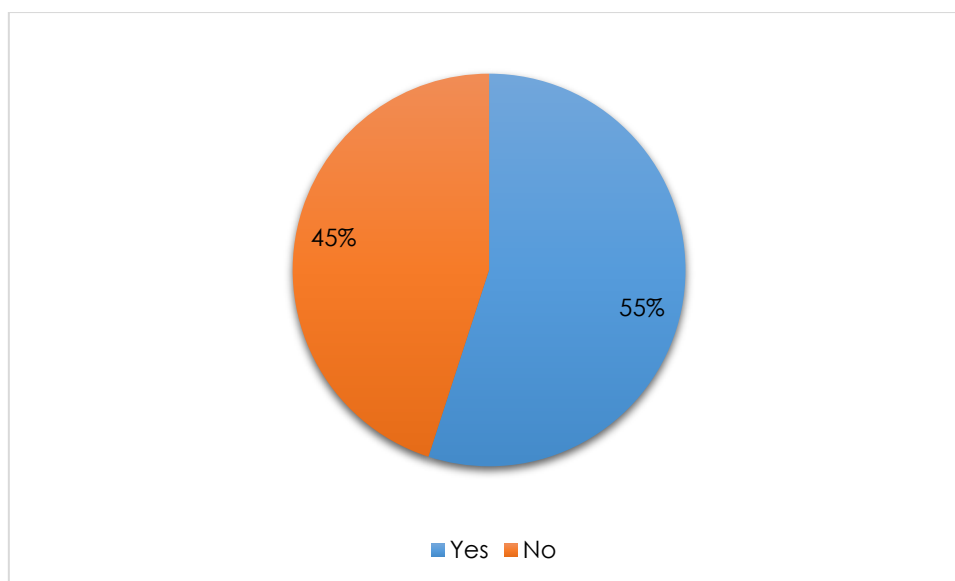
95% of AFMID (19 families) live at home and one AFMID (5%) lives in a group home.

**Q3: Does the person with intellectual disabilities go to school or college?**



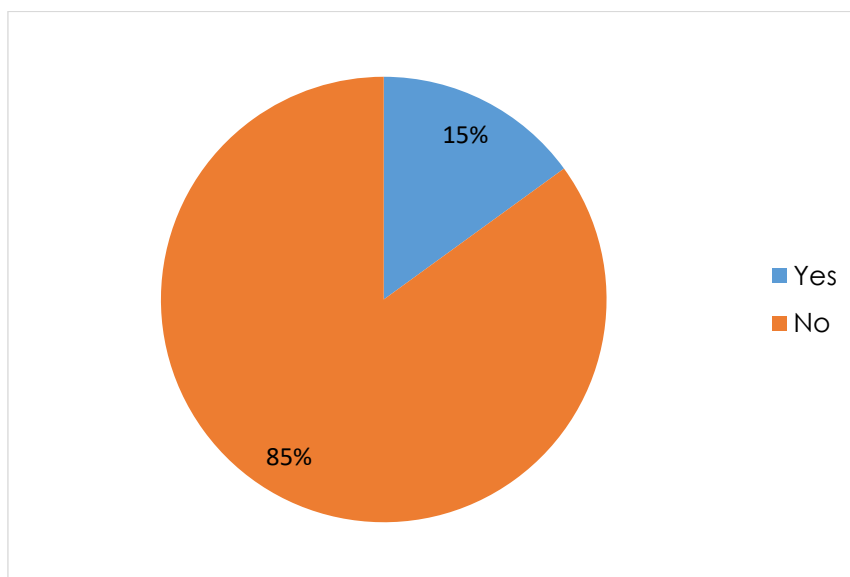
75 % (15 AFMID) have already finished school, 10 % (2 AFMID) are still in school and 15% (3 AFMID) are not in school.

**Q4: Does the person with intellectual disabilities go to any kind of day center or activity group?**



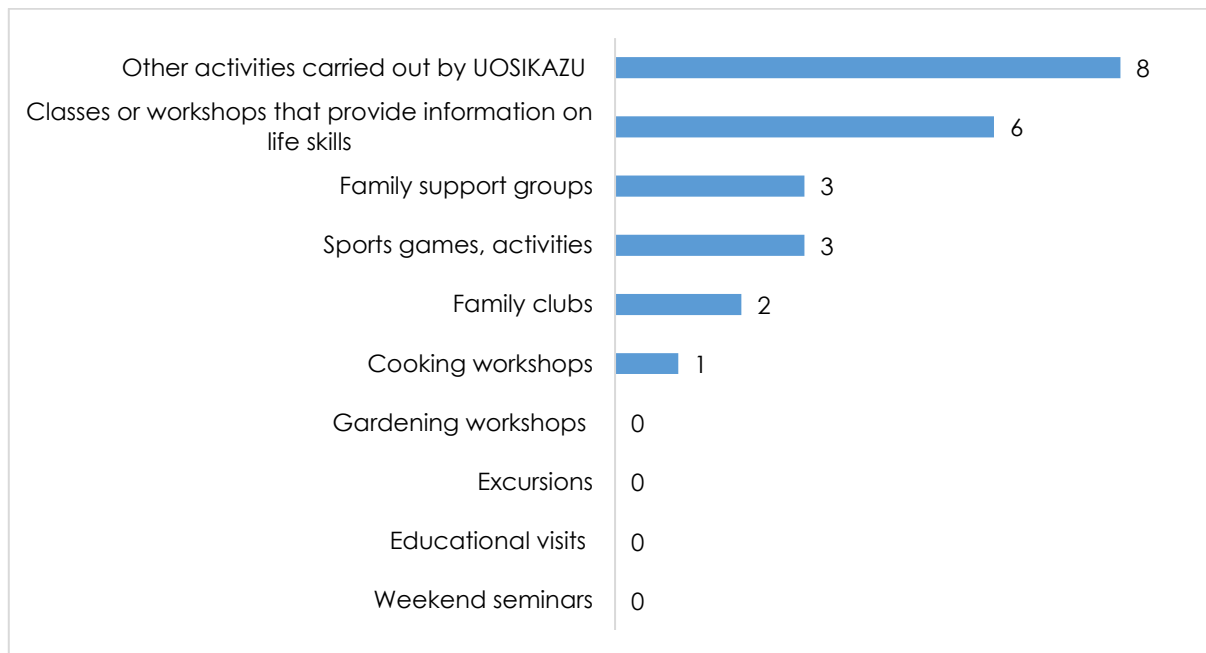
55 % of AFMID (11 persons) go to a day center or activity group and 45 % (9 persons) are not included in a day center.

**Q5: Are there opportunities close to your home for the person with intellectual disability to go to activities/classes with their family?**



15% of the interviewers (3 families) answered that there are opportunities close to their home to attend activities/classes together with AFMID. 85% (17 families) answered that there are no activities available close to their home. Nobody answered that there are activities available that just AFMID could attend.

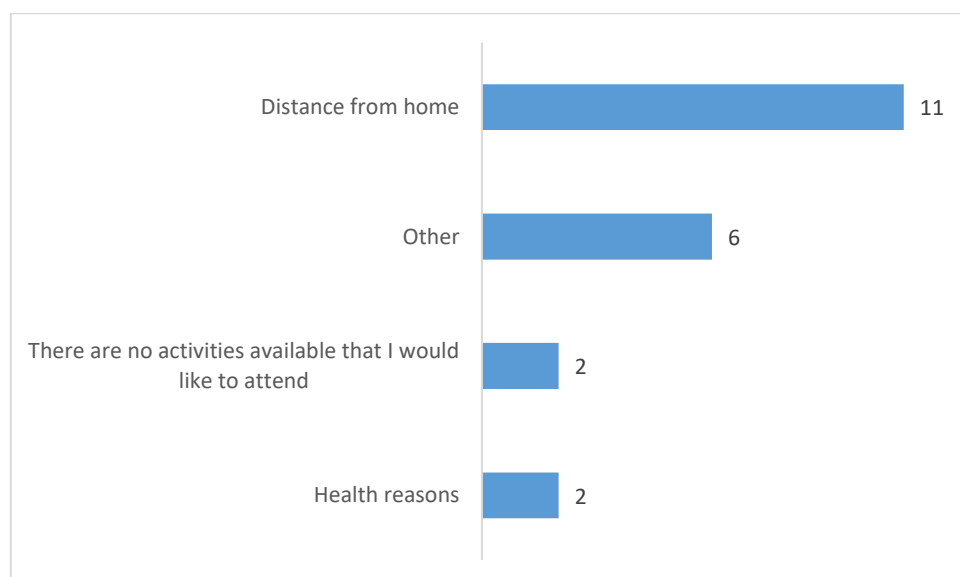
**Q6: Which activities/classes are available? (More than one answer possible.)**



Most frequently answered option was other activities carried out by UOSIKAZU (8 families answered this), following by classes or workshops that provide information on life skills (such as healthy living, legal rights, using money, etc.) families and sport activities.

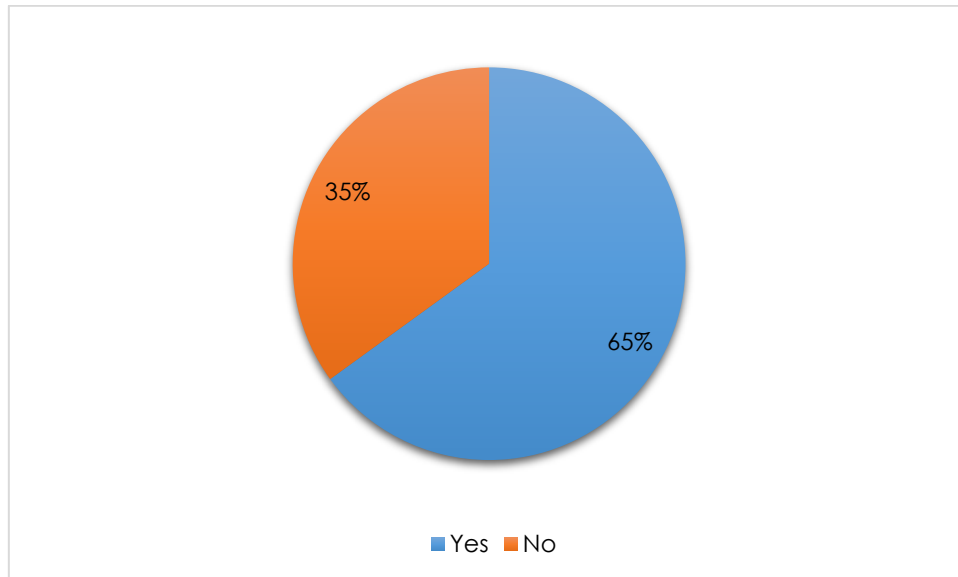
1 family answered that cooking workshops are available to them and none of the family answered that they have available gardening workshops.

**Q7: If you do not attend activities, what is the reason? (More than one answer possible.)**



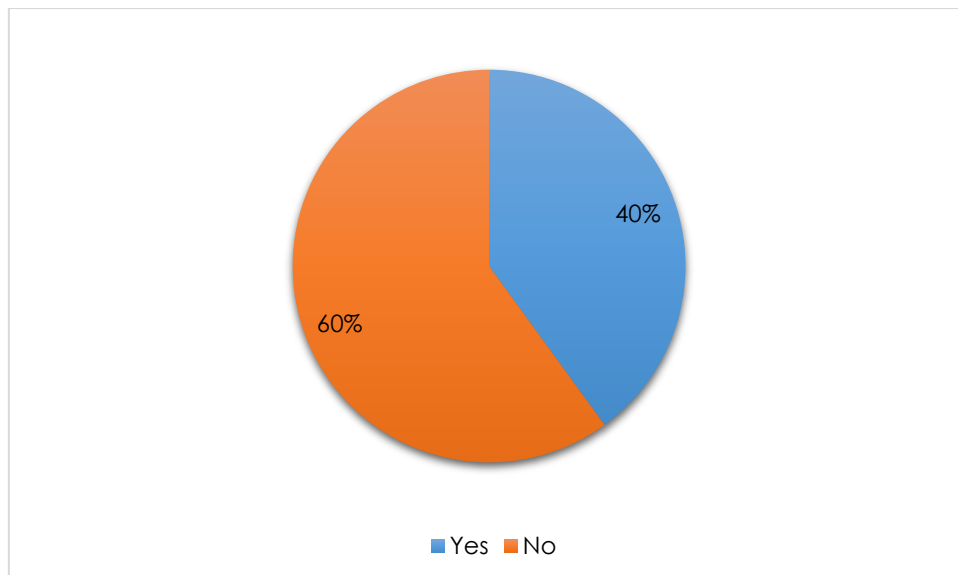
Most common answer to the question why the families do not attend activities was distance from home 11 out of 20 families stated that).

**Q8: Would you be interested in attending cooking workshops?**



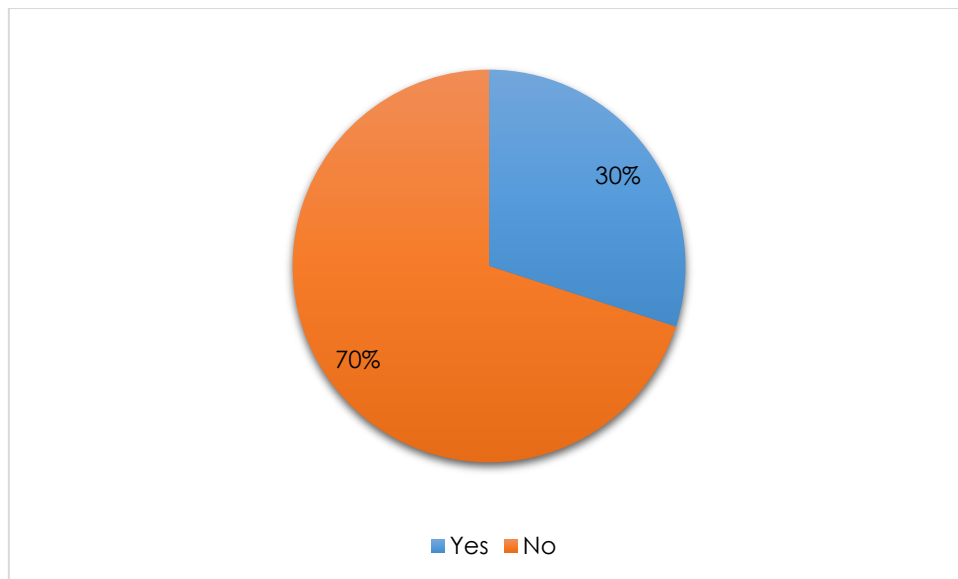
65 % (13 families) would attend cooking workshops, while 35 % (7 families) would not be interested in attending cooking workshops.

**Q9: Would you be interested in attending gardening workshops?**



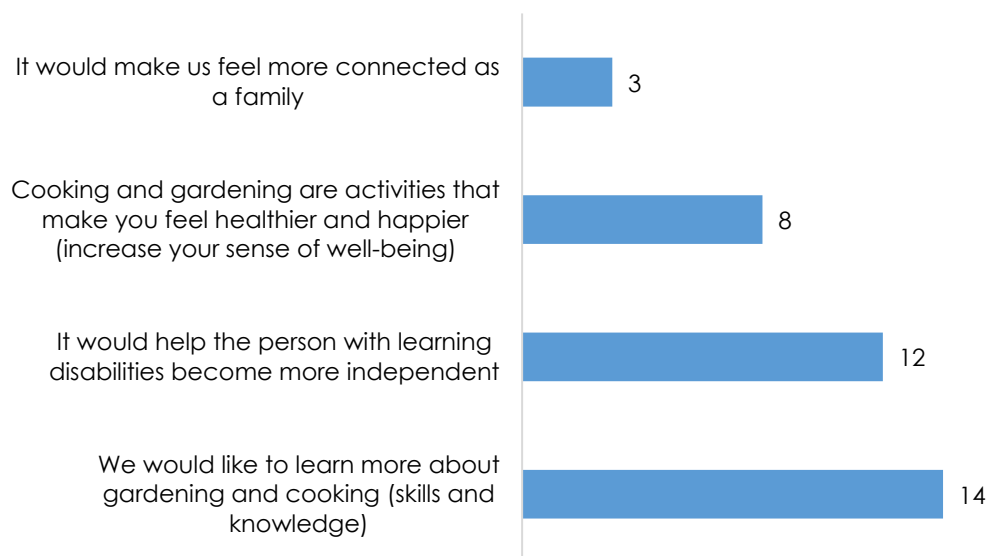
40 % of the families (8 families) would attend gardening workshops while 60 % of the families (12 families) would not attend this kind of workshops.

**Q10: Would the family (parents, brothers, sisters, etc.) be interested in attending cooking and gardening workshops together with the person with learning disability?**



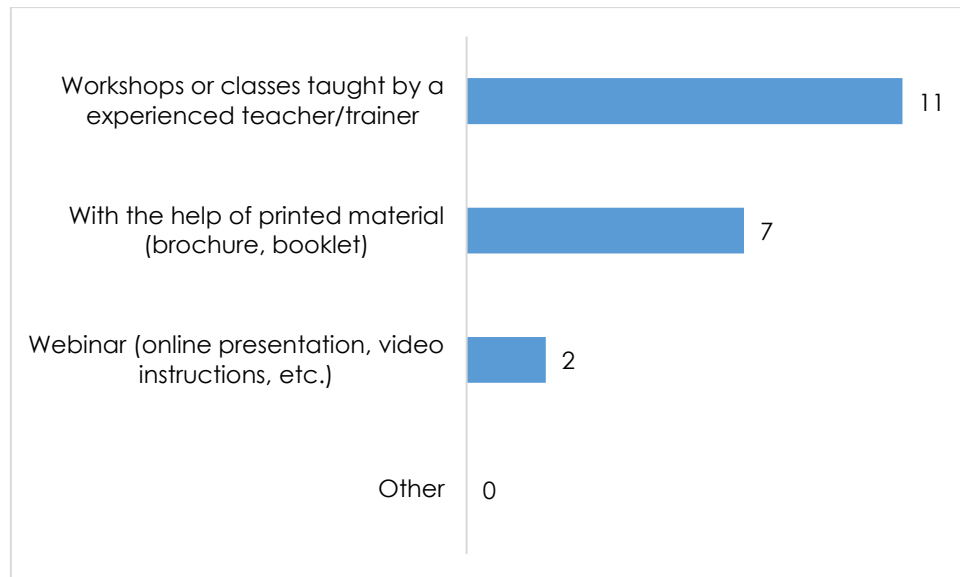
70 % of the families (14 families) answered that they would not attend workshops together with the AFMID, while just 30 % (6 families) would attend the workshops together with AFMID.

**Q11: Why would you attend these kind of activities (cooking and gardening workshops)? (More than one answer possible.)**



14 families answered that they would attend cooking and gardening workshops to gain new skills and knowledge, 12 families answered that this will provide AFMID with greater independence, 8 families answered that this activities provide you with better well-being and 3 families stated that this activities would connect them more as a family.

**Q12: How would you prefer to learn more about cooking and gardening? (More than one answer possible).**



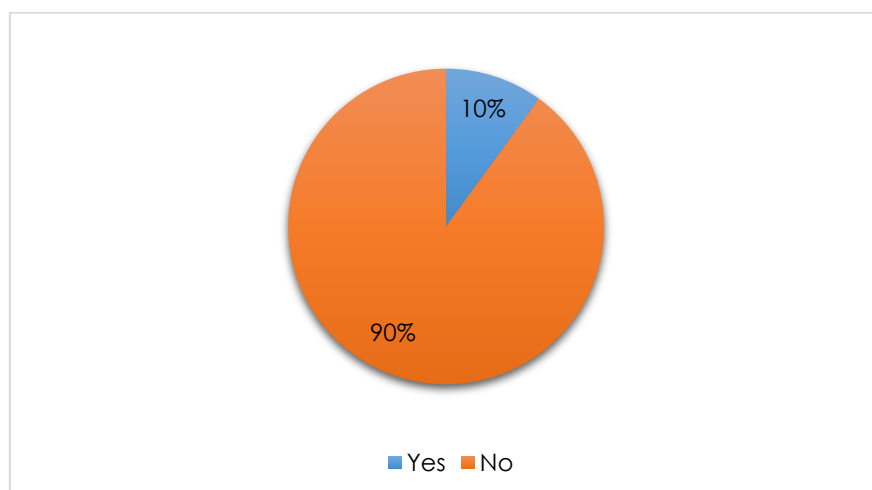
The majority (11 families) answered that they would like to learn about cooking and gardening in workshops or classes taught by an experienced trainer.

### **PART 3: QUESTIONS FOR ADULT FAMILY MEMBERS WITH INTELLECTUAL DISABILITIES**

**Q1: What is your favourite meal? (open question)**

Common answers were: pizza, pasta, bolognese, steak, chicken and some other simple meals.

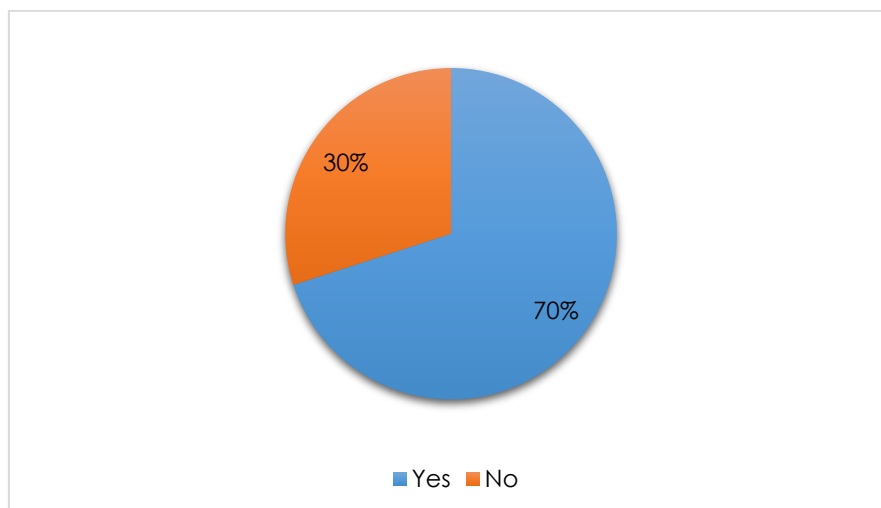
**Q2: Can you make or cook it yourself?**





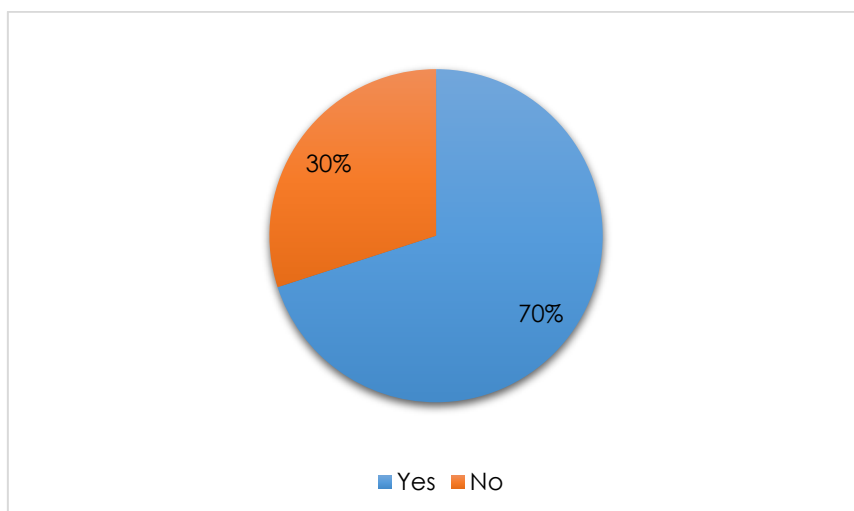
10 % (2 AFMID) answered that they can cook their favorite meal while 90 % (18 AFMID) answered they do not know how to cook their favourite dish.

**Q3: Would you make or cook it at home if you knew how to?**



70 % of AFMID (14 persons) answered they would make or cook the meal if they would know how, and 30% of AFMID (6 persons) answered they would not prepare it on their own.

**Q4: Would you like to grow your own fruit or vegetables for the meal? (plant the seeds, look after the plants as they grow and harvest the fruit or vegetables).**



70 % of AFMID (14 persons) would like to grow their own fruit or vegetables for the meal, while just 30 % (6 AFMID) would not like to grow it on their own.

### 3.2 Questionnaire summary

According to the results, almost all AFMID that participated in the questionnaires live at home and the majority visits a day center or activity group. Majority of the families and AFMID do not have opportunities to attend activities close to their

home. The most frequently stated reason why the families do not attend activities was, the distance from home. This confirms our assumptions that bringing education closer to home would be a good solution for the families to attend lifelong educational processes.

Most of the families and AFMID would be interested in gardening and cooking activities but the majority of the parents would not attend the workshops with their AFMID.

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

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## 5 NATIONAL REPORT 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

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 2020<sup>7</sup>.

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 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.

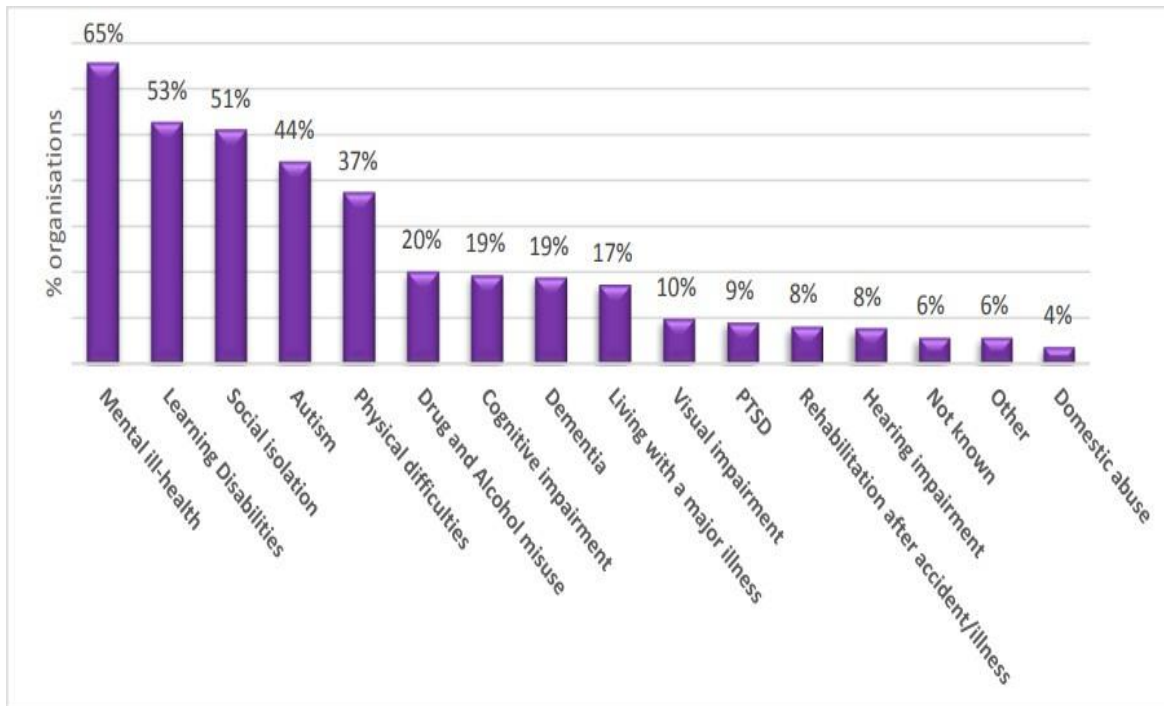


Figure 6 Categories of service -user accessing services

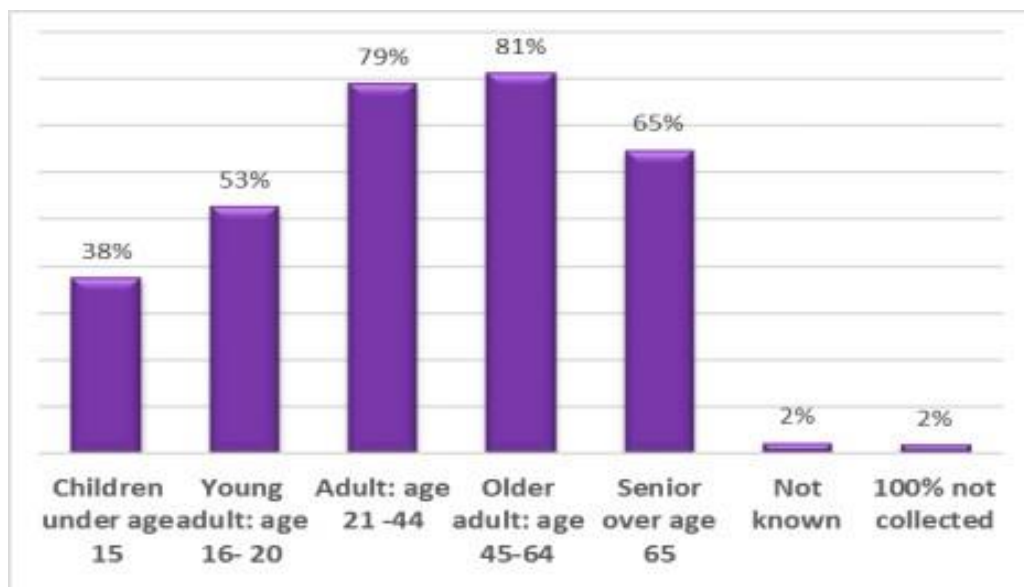


Figure 7 % Organisations with participants in each age category

Most 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 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.

The questionnaire has three main sections: the first gathers general information about the family, the second gathers answers from the family and the final three questions were designed to be answered by the individual with learning disabilities

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 who provide support for individuals with learning disabilities. Since we have not had response from these contacts, we have been approaching other organisations. 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 organisations who work with adults with learning disabilities.

The initial approaches described above failed to yield enough participants to produce useful information for this survey, so the questions from this survey were combined with the other MeTura surveys to produce a single survey for adults with learning disabilities and their families.

## QUESTIONNAIRE ANALYSIS

The questionnaire was divided into three parts; the first part consisted of general information on the family, the second part consisted of 12 closed questions to be answered by the whole family, while the third part consisted of one open and 3 closed questions and was intended for adult family members with intellectual disabilities (AFMID). This part was prepared in easy read form.

The aim of the questionnaire was firstly, to find out if the families and AFMID attend any educational or other activities. Secondly, we wanted to find out that if they do not attend activities, what are the reasons. We also wanted to discover whether the family was interested in attending activities together with their AFMID and specifically, whether they would be interested in attending therapeutic gardening and cooking. We also wanted to find out what benefits the families believe they would gain from this kind of activity.

Questionnaire was filled out by 23 families with AFMID.

### PART 1: GENERAL INFORMATION ABOUT THE FAMILY

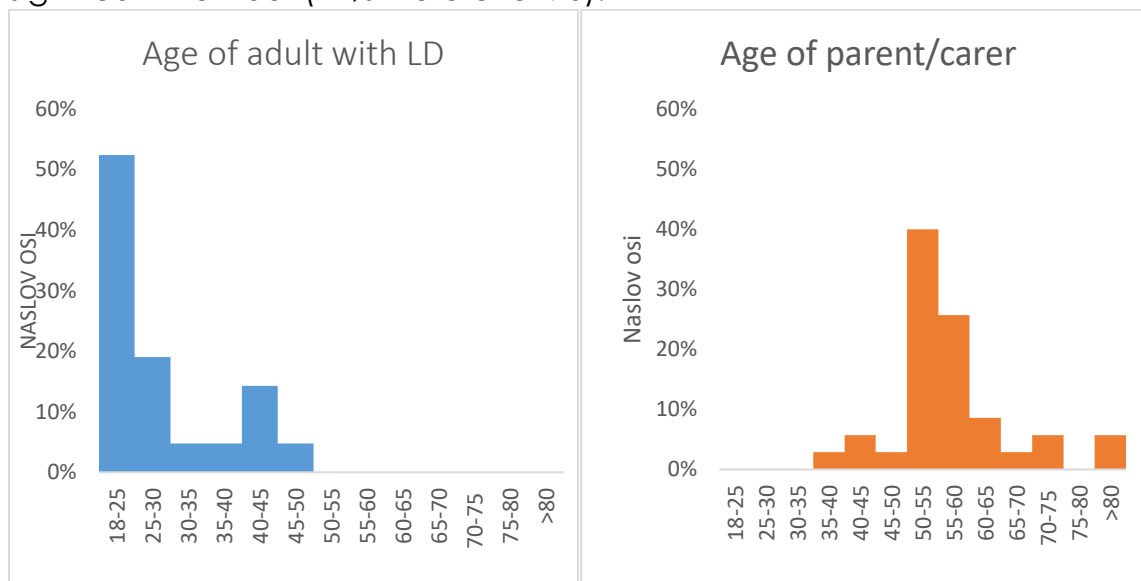
#### Age of parents and adult family members with learning disabilities (AFMID)

	Adult with LD	Parent/carer
male	57%	48%
female	43%	52%

The average age of AFMID were 29 but ages ranged from 18-47, with the majority being under 30 but 14% in the 40-45-year-old category. The average



age of parents/carers was 58 and the majority were aged 50-65 but a significant number (12% were over 70).



### Are there any other children with intellectual disabilities in the family?

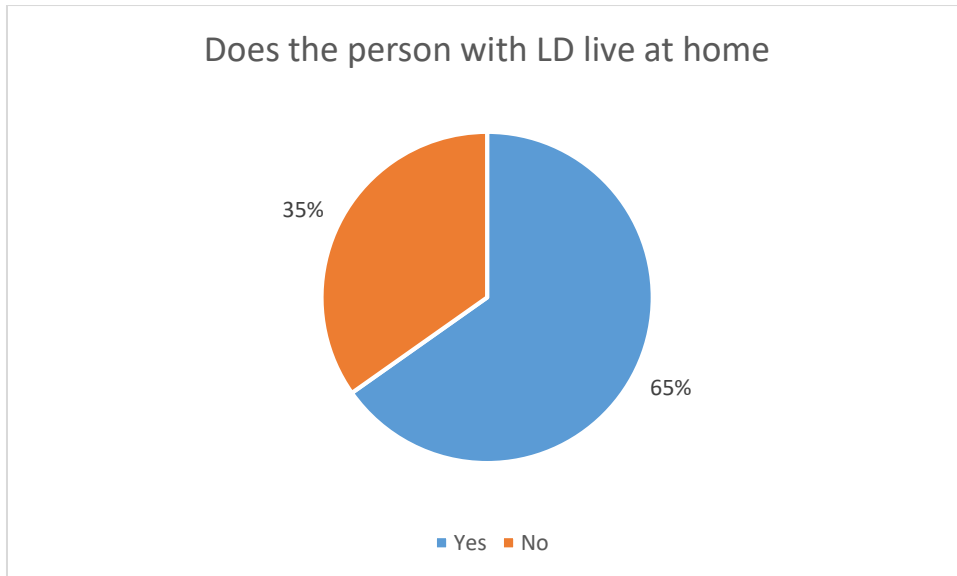
Only two families out of 23 (9%) had additional children with learning disabilities.

### Do either of the parents attend a day center or a supported activity group (as a participant)?

None of the parents in the survey attend a day center or supported activity group although 2 of the parents (9%) reported that they had a LD.

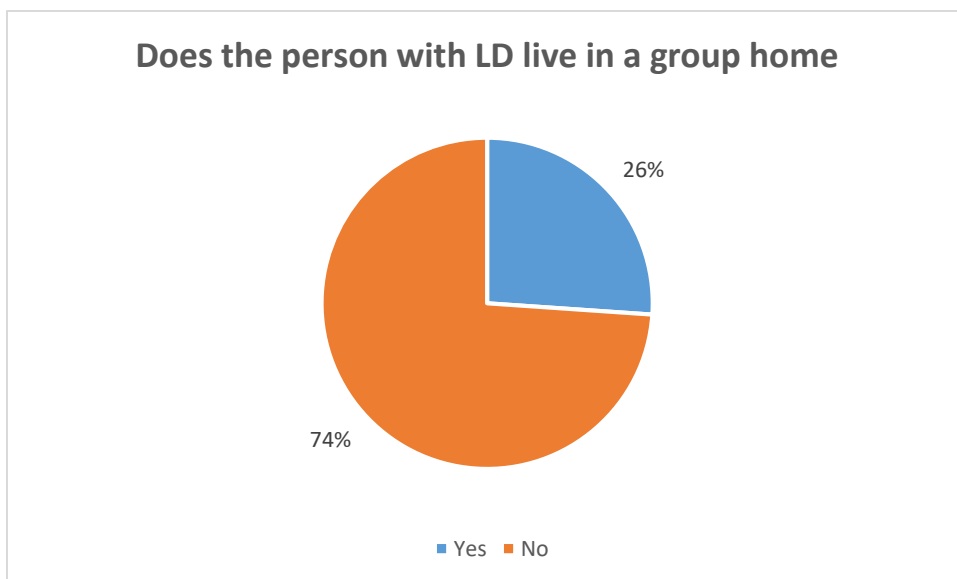
## PART 2: QUESTIONS FOR THE WHOLE FAMILY

### Q1: Does the person with intellectual disabilities live at home?



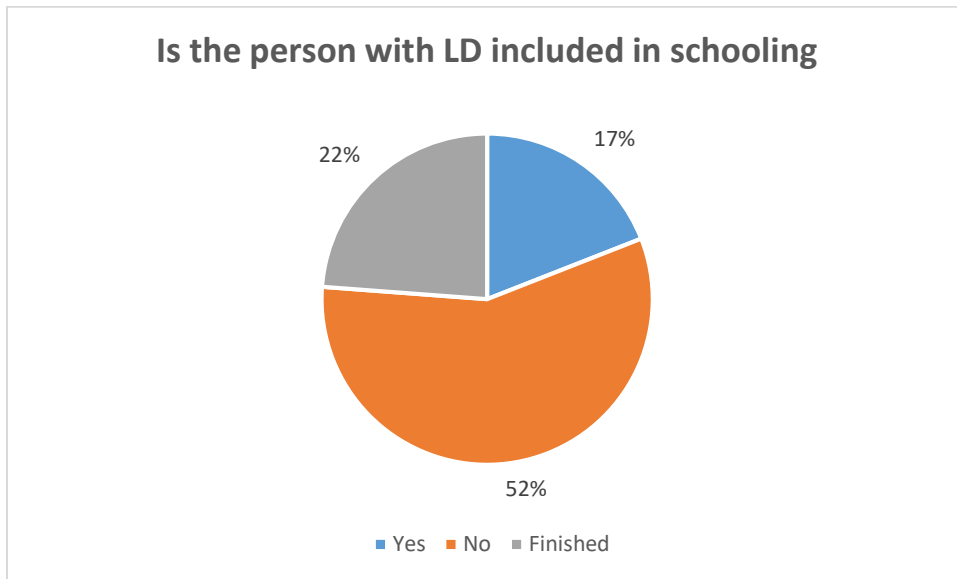
The AFMID lives at home in roughly 2/3 of the families surveyed.

**Q2: Does the person with intellectual disabilities live in a shared house or supported living?**

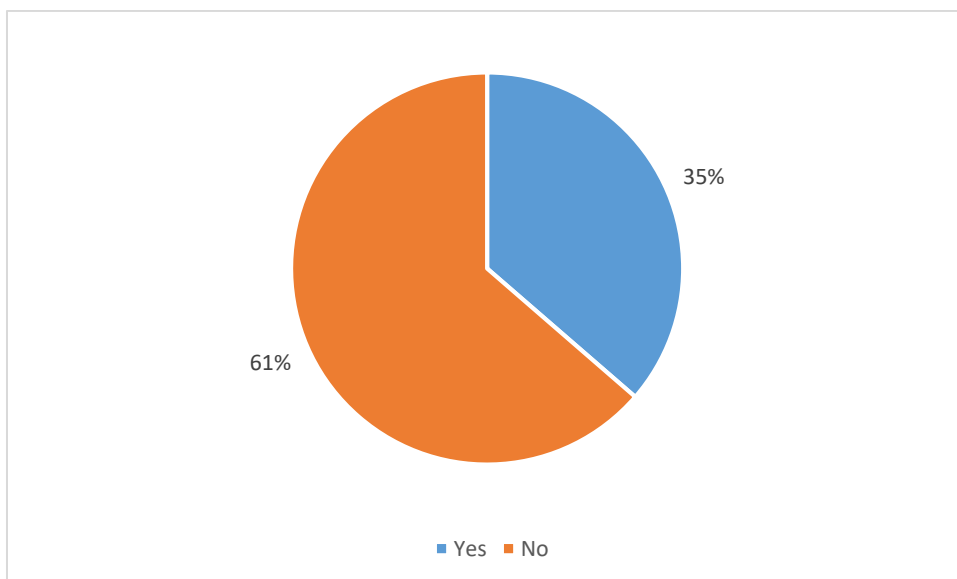


26% of the AFMID live in a shared house or supported living

**Q3: Does the person with intellectual disabilities go to school or college?**



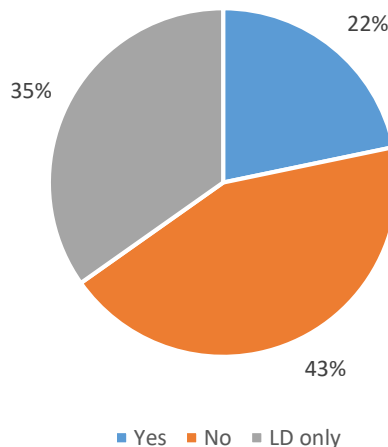
**Q4: Does the person with intellectual disabilities go to any kind of day center or activity group?**



35% of AFMID attend a day center of activity group

**Q5: Are there opportunities close to your home for the person with intellectual disability to go to activities/classes with their family?**

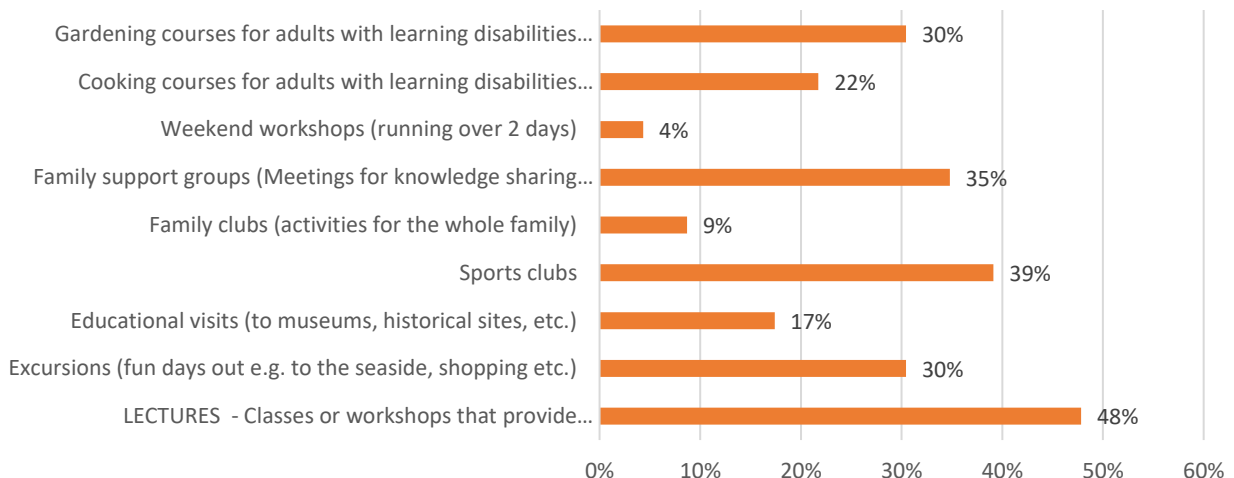
**Are there opportunities close to your home for the person with learning disability to go to activities/classes with their family?**



Only 22% of families answered that there were opportunities near to them for the family to attend activities with the AFMID. 35% reported classes for AFMID only and 43 % said there were no classes/activities close to home.

**Q6: Which activities/classes are available?**

**Which activities/classes are available in your local area? Who are these aimed at ? (Please select all that apply) Which activities/classes are available in your local area? Who are these aimed at ? (Please select all that apply)**

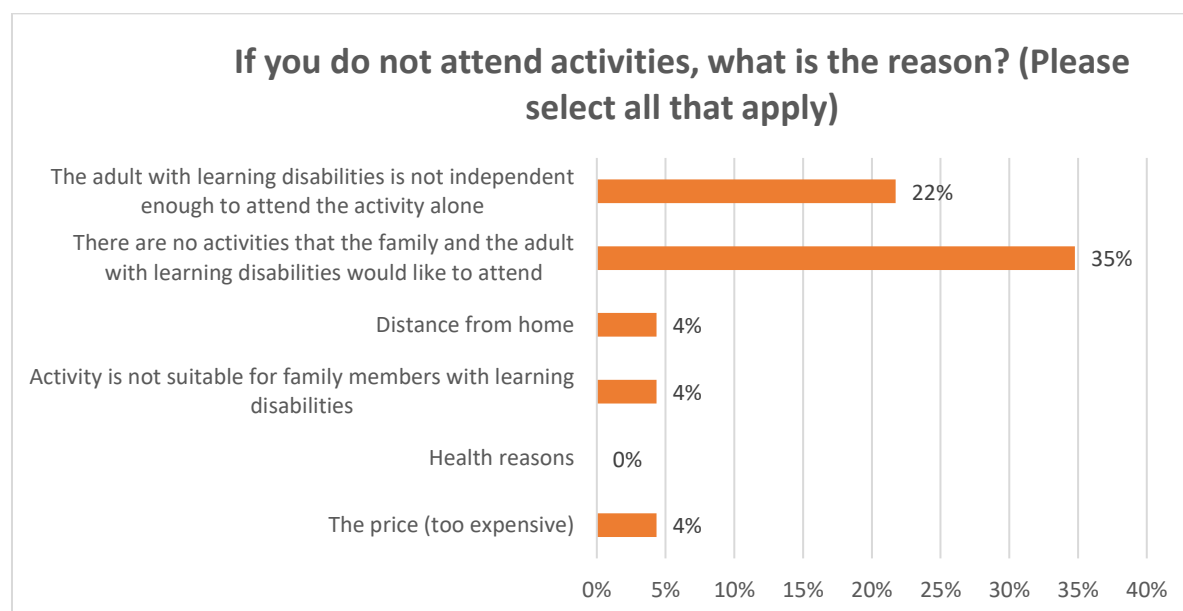


The most frequently reported activities were family support groups, sports clubs and classes/workshops. Gardening courses, excursions and cookery courses were the next most common. There were very few weekend workshops or family clubs.

### Comments & other activities

- Don't really know what is available in the local area. Being on the autism spectrum means any social contact would be difficult anyway even if we knew about it.
- Courses attended are. IT and craft and the gym
- Most of the above are available at day service only.
- Lot of activities or courses that are listed above are aimed at the carers and not the person with the learning disability
- Day centres Adult with LD only
- I am in the process of setting up activities which can be accessed by people with learning difficulties in my area as there is nothing here for them to do.
- He attends music school, cookery activity, Thrive, a local gym, a leisure centre for swim, gym and spa, voluntary gardening activity, trampolining, ice skating, and the sports club is sailing. He has started art therapy. He is always accompanied as he is profoundly deaf, sight impaired, and in the autistic syndrome in addition to his learning disability

### Q7: If you do not attend activities, what is the reason? (More than one answer possible.)

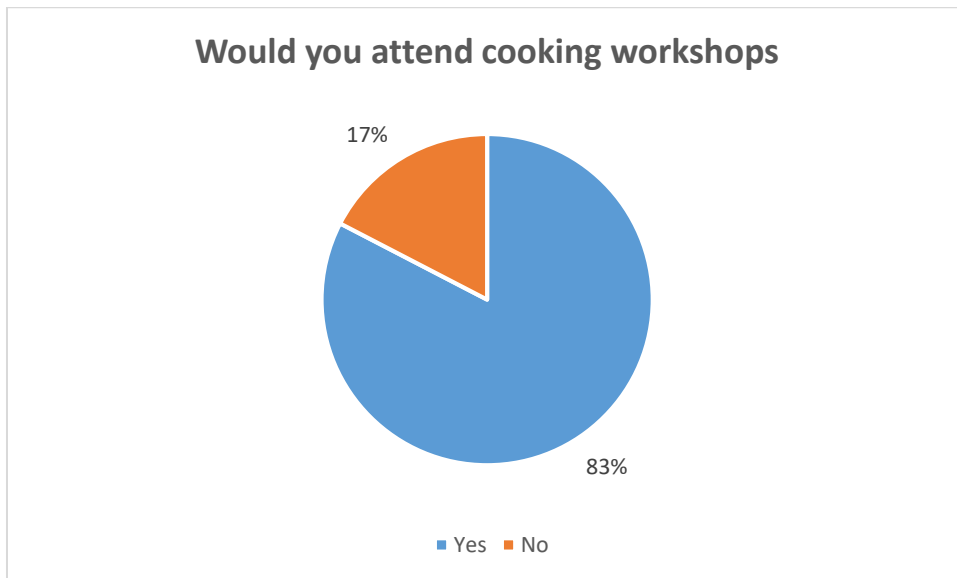


The main reasons given were that there were no activities that the AFMID and family would like to attend or that the AFMID was not independent enough to attend alone. She does not want to attend

### Comments

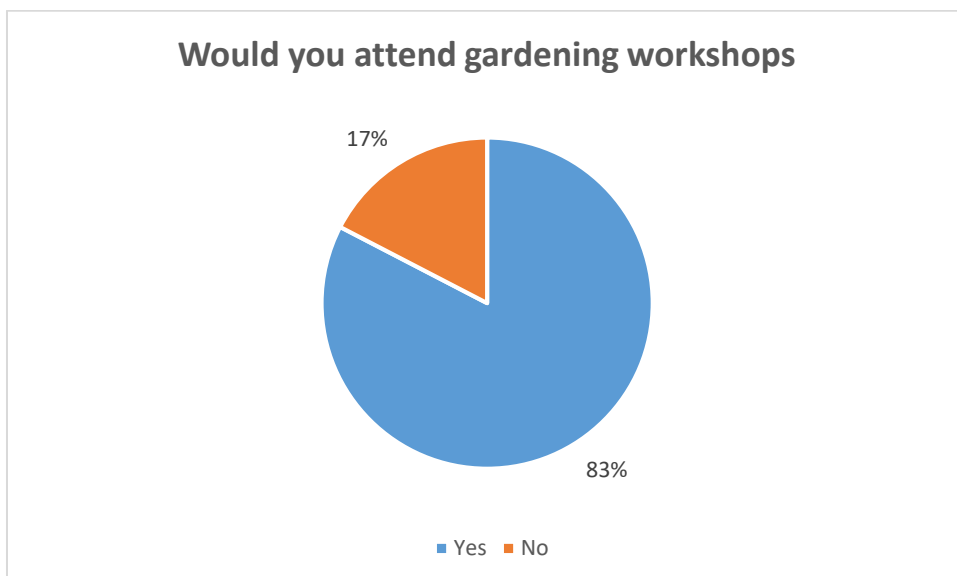
- Aren't any courses anyway as far as we are aware. Nobody has told us anything about any.
- Not aware of any courses or organized activities for people with LD to attend with family
- The nearest activity is 15 miles away
- Not aware of activities in local area

**Q8: Would you be interested in attending cooking workshops?**

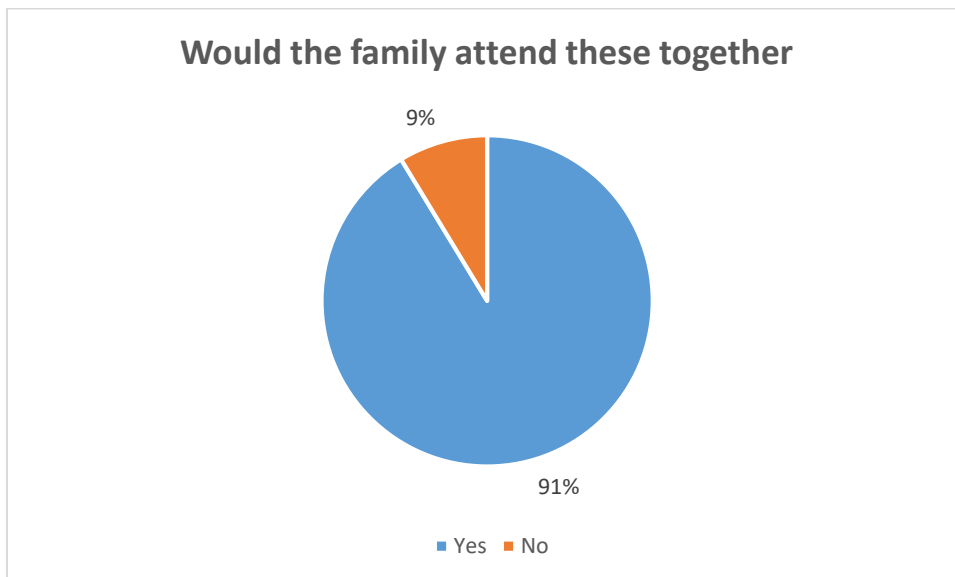


83% of families would be interested in cooking workshops

**Q9: Would you be interested in attending gardening workshops?**

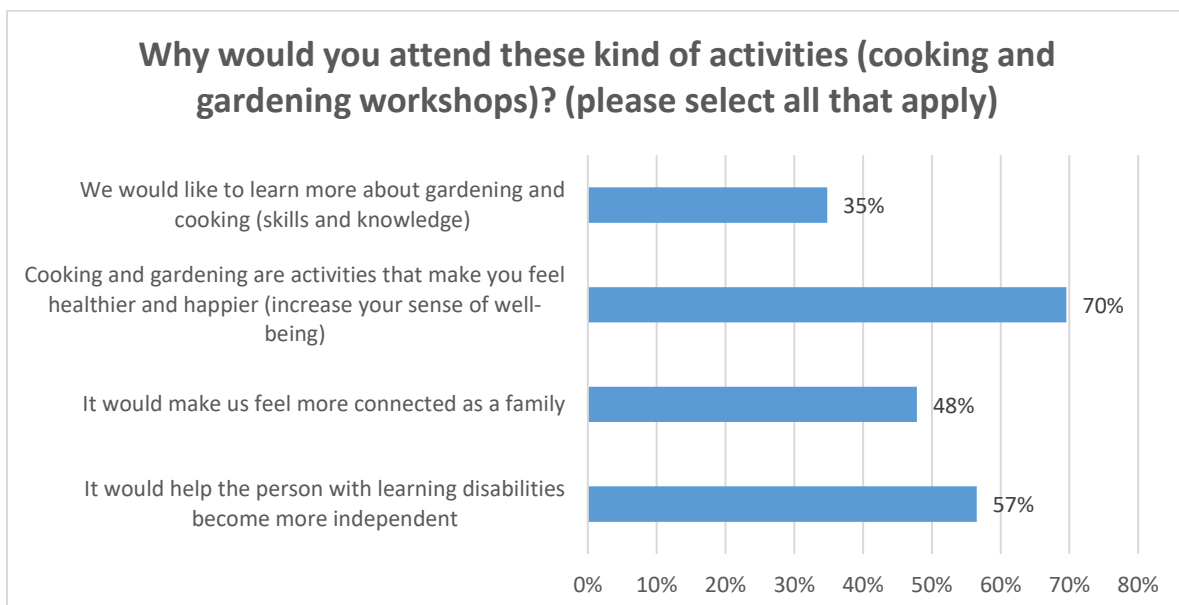


**Q10: Would the family (parents, brothers, sisters, etc.) be interested in attending cooking and gardening workshops together with the person with learning disability?**



91% of families would be interested in attending workshops together with the AFMID

**Q11: Why would you attend these kind of activities (cooking and gardening workshops)?**



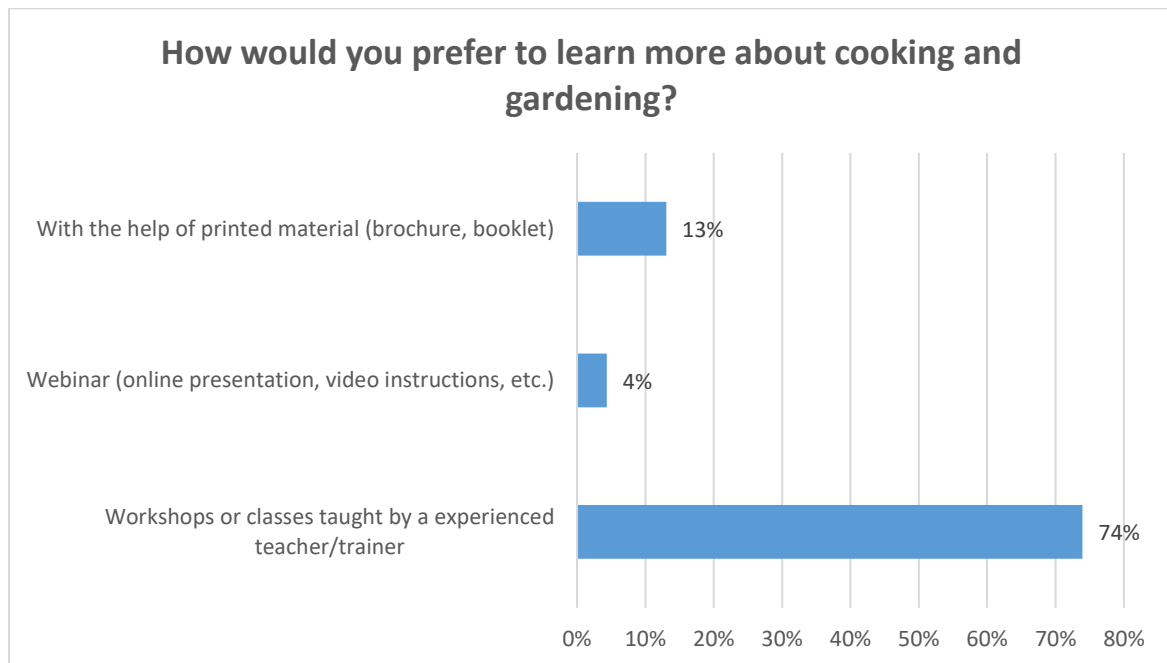
The primary reason that families reported was the improvement in health and wellbeing (70%). Independence and skills and knowledge were the next most

popular reason. Family connection was selected by just under ½ of the participants.

Other reasons

- It would be fun!
- Support one another but this potentially wouldn't happen because of Autism and unlikely to actually attend a social event at the end of the day.
- Main goal is to prepare for the future in being more able to do basic tasks

#### Q12: How would you prefer to learn more about cooking and gardening?



The overwhelming majority of families wanted to learn by workshops or classes with an experienced trainer

### PART 3: QUESTIONS FOR ADULT FAMILY MEMBERS WITH INTELLECTUAL DISABILITIES

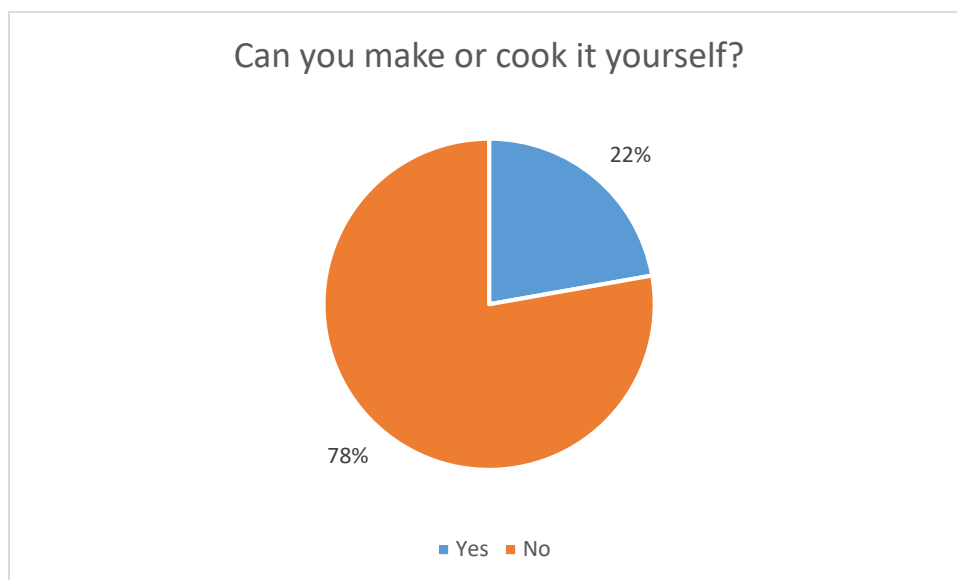
#### Q1: What is your favorite meal? (open question)

The most common answers involved "comfort or less healthy food" such as chips (pie and chips, fish and chips,), sausage and waffle. Some clients wanted to make simple meals such as pumpkin soup or pasta with tomato sauce and



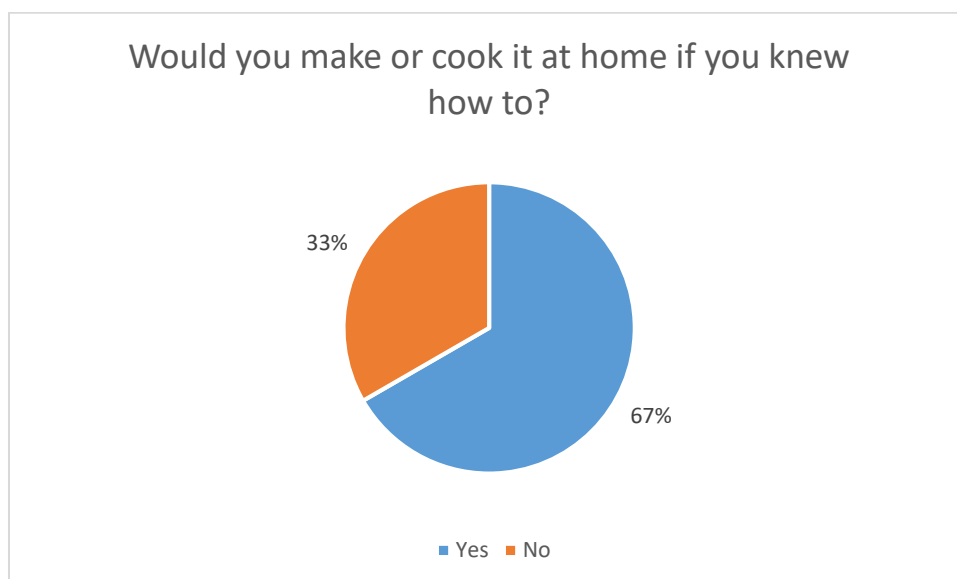
some wanted to make more complicated meals such as chicken korma or potato bake with vegetables. The choice of meal may depend on the level of ability of the client.

## Q2: Can you make or cook it yourself?



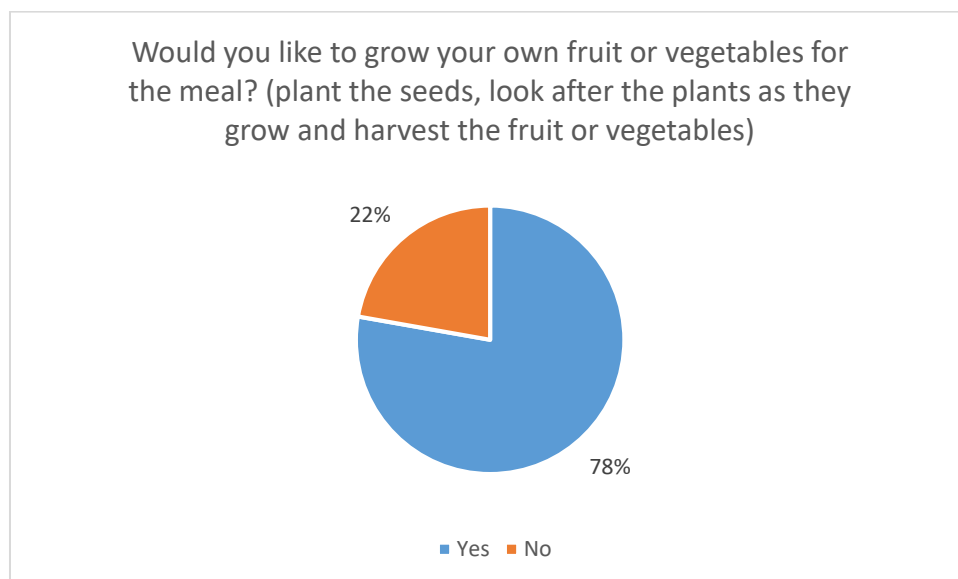
Although the majority of AFMID reported that they could not make it themselves, most of these also said that they could cook it “with help”.

## Q3: Would you make or cook it at home if you knew how to?



67% said that they would cooking it at home if they knew how to. Some of the meals selected are common “takeaway” meals (such as fish and chips), so it may be that the respondents like being able to buy/eat the meal with little or no effort!

**Q4: Would you like to grow your own fruit or vegetables for the meal? (plant the seeds, look after the plants as they grow and harvest the fruit or vegetables).**



78% of respondents would like to grow their own fruit or vegetables for the meal.

## QUESTIONNAIRE SUMMARY

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 healthier, 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 can not 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 in growing the ingredients.

## 5.7 References

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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 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”.

## 7 ANNEX

### Questionnaire O1 – Bringing family education closer to home

#### INSTRUCTIONS FOR FILLING OUT THE QUESTIONNAIRE

The questionnaire is anonymous. Results will be used only for the needs of the project Family Education MeTURA – Back to the roots. Project is result of the partnership of 4 countries (Slovenia, UK, Italy and Croatia) and will develop innovative ways how to bring education closer to home.

Part of the questionnaire is filled out by the whole family and part of the questionnaire is filled out only by the person with intellectual disabilities. When answering, choose one option or write down your own answer, or circle more answers, if it is written so.

#### GENERAL DATA

Age of the person with intellectual disability: .....

Age of parent 1: .....

Age of parent 2: .....

**There are more children with intellectual disabilities in the family**

- a) Yes
- b) No

**Also parents are included in occupational activity center**

- a) One of the parent is included in occupational activity center
- b) Both of the parents are included occupational activity center

- c) No, parents are not included in the occupational activity center

## QUESTIONS FOR THE WHOLE FAMILY

### 1. Does the person with intellectual disability live at home?

- a) Yes
- b) No

### 2. Does the person with intellectual disabilities live in a group home?

- a) Yes
- b) No

### 3. Is the person with intellectual disabilities included in schooling?

- a) Yes
- b) No
- c) He/she already finished schooling

### 4. Is the persons with intellectual disabilities included in any kind of occupational activity center?

- a) Yes
- b) No

### 5. Do you have, in the environment close to your home, opportunities to attend activities / trainings for persons with intellectual disabilities and their parents?

- a) Yes
- b) No
- c) There are activities available, but just for persons with intellectual disabilities

### 6. Which activities are available? (You can circle more answers.)

- a) Lectures
- b) Excursion
- c) Guided visits of institutions
- d) Sport games, activities
- e) Club of parents, kids, families



- f) Meetings for exchanges experiences among families
- g) Weekend seminars
- h) Cooking workshops
- i) Gardening workshops
- j) Other:.....

**7. If you do not attend activities, what is the reason? (You can circle more answers.)**

- a) The price
- b) Health reasons
- c) Activity is not adjusted to the family
- d) Distance from home
- e) There are no activities available, that I would like to attend
- f) Lack of independence of the person with intellectual disability for him/her to attend the activity alone
- g) Other....

**8. Would you attend cooking workshops?**

- a) Yes
- b) No

**9. Would you attend gardening workshops?**

- a) Yes
- b) No

**10. Would the family (parents, brothers, sisters) attend cooking and gardening workshops together with the person with intellectual disability?**

- a) Yes
- b) No


**11. Why would you attend this kind of activities (cooking and gardening workshops)? (You can circle more answers.)**

- a) This would give the person with intellectual disability greater independence
- b) We feel more connected as a family
- c) This activities offer well-being

- d) Gaining new knowledge
- e) Other:.....

**12. In which way would you wish to gain knowledge for performing activities of cooking and gardening?**

- a) Workshops, trainings with mentors
- b) Webinar (online presentation, video instructions)
- c) With the help of printed material (brochure, booklet)
- d) Other:.....

Write  or circle the answer.<sup>i</sup>

## QUESTIONS FOR PERSONS WITH INTELLECTUAL DISABILITIES

Which is your favorite dish?

Write: .....



Can you prepare it yourself?

- a) Yes
- b) No



Would you prepare it at home if you would know how to?

- a) Yes
- b) No



Would you wish to grow (plant the seeds, water the plant,..) the ingredients for the dish yourself?

- a) Yes
- b) No



<sup>i</sup> Author of the drawings is Zoran Smiljanić and were made within the project »Lahko je brati«