

**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 IO3, Study of motivational support methods of educators for more effective social activation of families and their adult family members with intellectual disorders**

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

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## 1 INTRODUCTION

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

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

- effective communication strategies of educators in their involvement in LL for adults, social activation;
- to find key inclusive communication system gaps and the necessary systematic and individual assistance infrastructure for integrating into the planned independent implementation of the LL in families;

- which methods of publishing, implementing and using supportive learning tools are most effective for target groups: printed, CD, movies, audio recordings, FB publications, web pages, ...
- the methods and strategies for effectively disseminating and using the results of the project among the target groups of adults; where the target groups potentially perceive the greatest difficulties in accessing the results of the project;
- identify the necessary communication skills of educators, learning families and vulnerable adults, the content of psycho-education, including communication through social networks for more effective social activation.

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

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

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

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

## 2. NATIONAL REPORT SLOVENIA

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

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

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

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

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

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

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

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

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

## 2.1 LIFELONG LEARNING OF ADULTS WITH INTELLECTUAL DISABILITIES

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

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

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

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

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

## 2.2 GOOD PRACTICE EXAMPLES IN SLOVENIA

### CMEPIUS

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

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

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



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

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

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

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

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

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

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

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

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

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

## 2.3 REFERENCES

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## 2.4 EDUCATOR QUESTIONNAIRE ANALYSIS

The questionnaire was divided in two parts. First part consisted of some general information about educators, second part consisted of questions about communication between families with AFMID and educators.

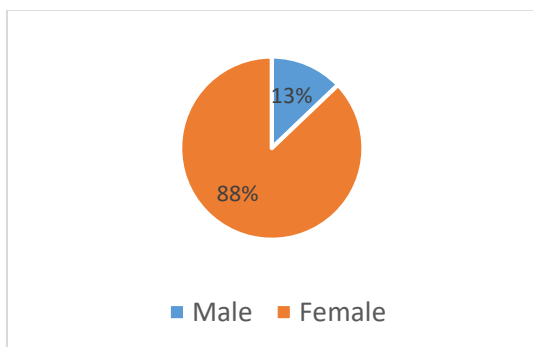
With this questionnaire we wanted to find out how do educators communicate with families with AFMID and what are the main barriers in communication. We also wanted to know what methods are used by educators in their work with families with AFMID.

Next, we wanted to know what problems do educators encounter in the process of LL of families with AFMID and how do they solve these problems. We wanted to find out what kind of support would educators need in their work with families with AFMID.

Further, we asked the educators what do they think are the reasons families with AFMID do not engage in LL activities and how this could be encouraged. We asked the educators on their opinion about how to motivate families with AFMID and what are the good practises in LL education of AFMID.

### Gender (n=24)

88% of educators that participated in the questionnaire are female, 12% are male.

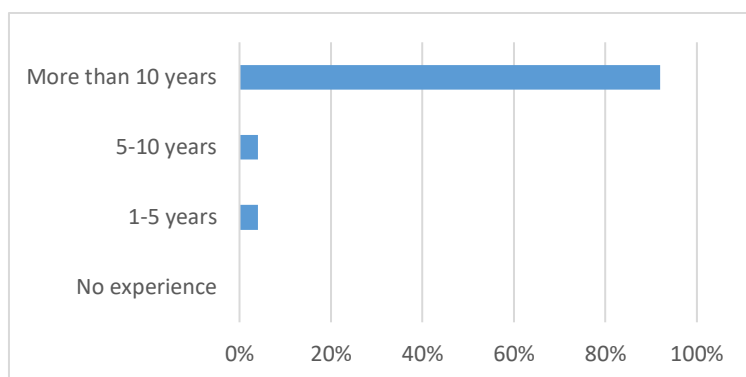


### Age (n=24)

The age of educators that participated in the questionnaire ranges from 40 to 70 years, the average age is 55 years.

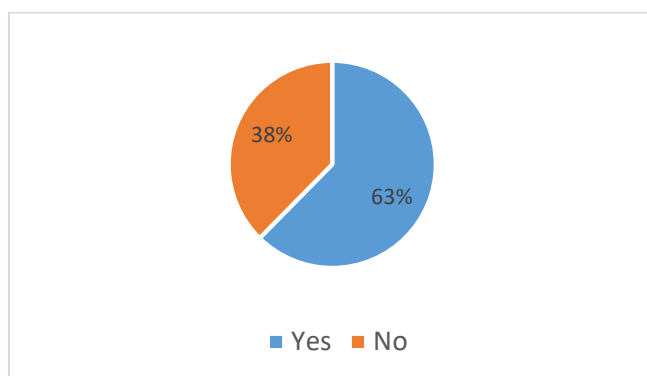
### How many years of experience (formal and non-formal) do you have working with families with AFMID? (n=24)

92% of educators that participated (22 participants) in the questionnaire have more than 10 years of experience working with families with AFMID. 4% of educators have 1-5 years of experience and 4% have 5-10 years of experience working with families with AFMID.



### Is it easy to get in touch with families with AFMID? (n=24)

63% of educators (15 participants) that participated in the questionnaire think it is easy to get in touch with families with AFMID, 38% (9 participants) think it is difficult to get in touch with them.



### If no, what are the main obstacles in the communication? (n=9)

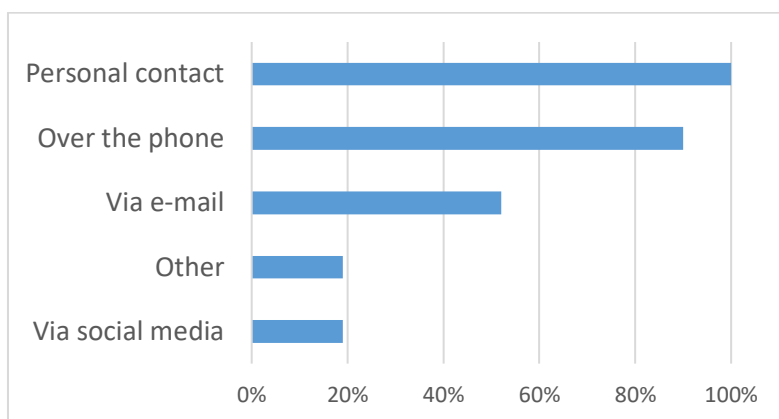
Answers given:

1. Families are in denial about their child's condition; they do not accept the fact that their child is different (n=6)
2. Parents with AFMIDs are not trustful in the beginning (when they have the child); they need time to adapt to the situation (n=1)
3. Families with AFMIDs tend to seclude themselves from surrounding environment (n=1)
4. Young families with AFMIDs believe they get enough information from the internet (n=1)

### What channels of communication with families with AFMID do you mostly use? (n=21)

All of educators that participated in the questionnaire communicate with families in person, 90% (19 participants) use the phone and 52% (11 participants) use the e-mail. 19% of educators that participated in the questionnaire communicate via social networks and 19% (4 participants) use other ways of communication, which are:

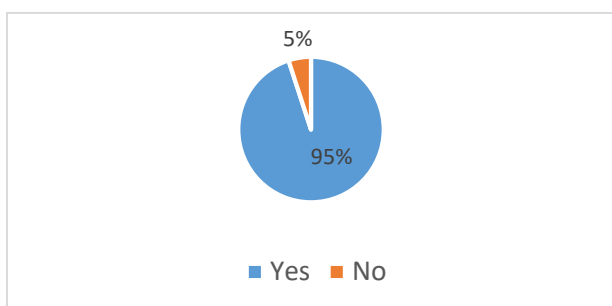
1. Leaflets
2. Participating in activities and day-trips
3. Home visitations
4. Local activities offered by local Sožitje societies



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**When AFMID is included in your organisation, do you perform any kind of meeting/interview/ conversation with their family to determine their educational need/preference? (n=21)**

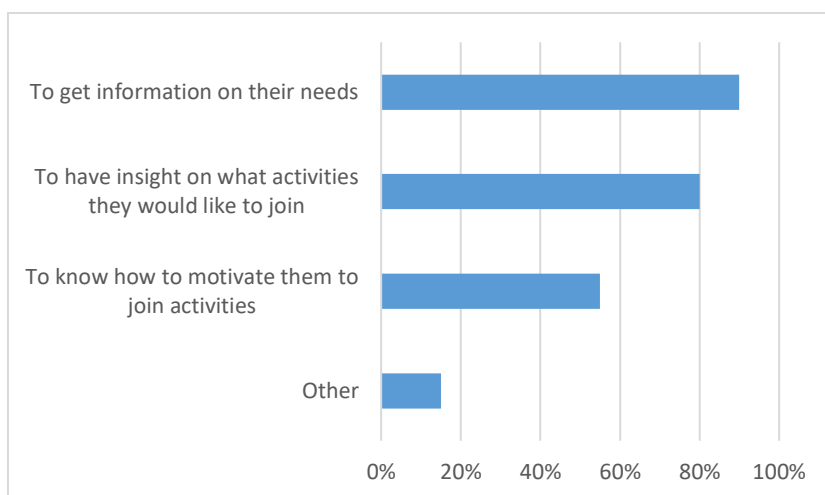
95% of educators (20 participants) that participated in the questionnaire perform meetings/interviews/conversation to assess the needs of AFMID, while 5% (1 participant) do not.



**If yes, why do you think it's useful? (n=20)**

90% of educators (18 participants) that participated in the questionnaire think it is useful for gaining information about their needs. 80% of educators (16 participants) that participated in the questionnaire think that interviews are useful for insight of preferred activities. 55% of educators (11 participants) that participated in the questionnaire think that meetings give them the knowledge on how to motivate families to join these activities. 15% (3 persons) of educators that participated in the questionnaire replied "other". Among those, three answers were given:

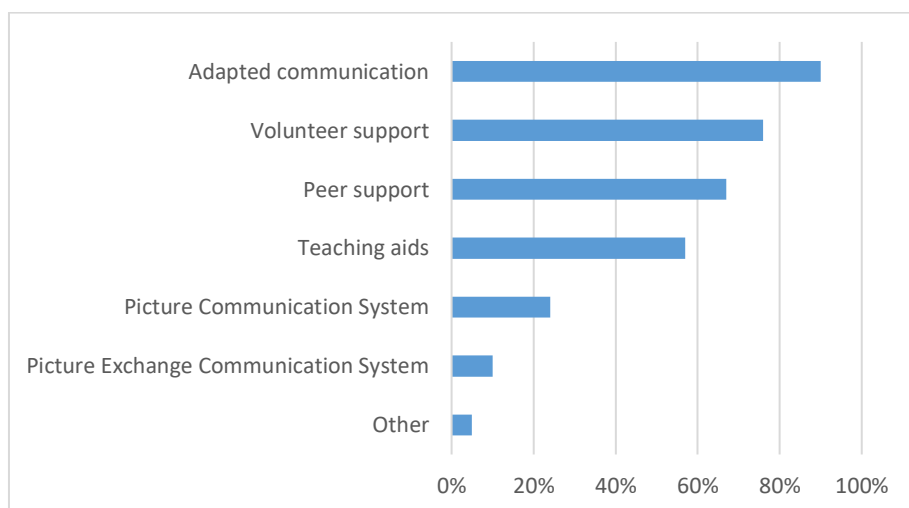
1. Sometimes the conversations with families allows the families to decide if they want to join the activities; gives them time to think about options
2. Personal contact is still the most important
3. Preserving acquired knowledge and skills



### What kind of methods do you use in your activities to get the AFMIDs involved? (n=21)

90% of educators (19 participants) that participated in the questionnaire use adapted communication in their work with AFMIDs. 76% of educators (16 participants) that participated in the questionnaire use volunteer support, 67% (14 participants) use peer support in their work. 57% of educators (12 participants) that participated in the questionnaire use teaching aids in their work with AFMIDs. 24% of educators (5 participants) that participated in the questionnaire use Picture communication system and 10% (2 participants) use Picture exchange communication system in their work. In section "other", one answer was given:

- Inclusion in social activities – socialization and independence.



### How important are the following features in communication with AFMIDs? (n=21)

1. RESPECT: 90% of educators (19 participants) that participated in the questionnaire think that respect is very important in communication with AFMIDs. 10% (2 participants) think it is important.

2. LISTENING: 86% of educators (18 participants) that participated in the questionnaire think that listening is very important in communicating with AFMIDs. 10% (2 participants) think listening is important, 5% (1 participant) think listening is of medium importance.
3. FRIENDLINESS: 81% of educators (17 participants) that participated in the questionnaire think that friendliness is very important in communication with AFMIDs. 19% (4 participants) think that friendliness is important.
4. PATIENCE: 86% of educators (18 participants) that participated in the questionnaire think that patience is very important in communication with AFMIDs. 10% (2 participants) think that patience is important. 5% of educators (1 participant) think that patience is of medium importance.
5. EMOTIONAL INTELLIGENCE: 81% of educators (17 participants) that participated in the questionnaire think that emotional intelligence is very important. 19% (4 participants) think that emotional intelligence is important.
6. COHESION AND CLARITY: 76% of educators (16 participants) that participated in the questionnaire think that cohesion and clarity are very important in communication with AFMIDs. 24% (5 participants) think that cohesion and clarity are important communication features.
7. OPEN MINDEDNESS: 71% of educators (15 participants) that participated in the questionnaire think that open mindedness is very important. 24% (5 participants) think that open mindedness is important. 5% of educators (1 participant) think that open mindedness is of medium important in communication with AFMIDs.
8. CONFIDENCE: 52% of educators (11 participants) that participated in the questionnaire think that confidence is very important in communication with AFMIDs. 29 % (6 participants) think that confidence is important. 14% of educators (3 participants) think that confidence is of medium importance in communication with AFMIDs. 5% (1 participant) think that confidence is of small importance in communication.
9. EMPATHY: 55% of educators (11 participants) that participated in the questionnaire think that empathy is very important with communication with AFMIDs. 20% (4 participants) think that empathy is important. 20% of educators (4 participants) think that empathy is of medium importance in communication with AFMIDs. 5% (1 participant) think that empathy is not important in communication with AFMIDs. One participant did not answer this particular feature.
10. BEING FIRM: 33% of educators (7 participants) that participated in the questionnaire think that being firm is of medium importance in communication with AFMIDs. 29% (6 participants) think that being firm is very important, and 24% (5 participants) think it is important. 14% of

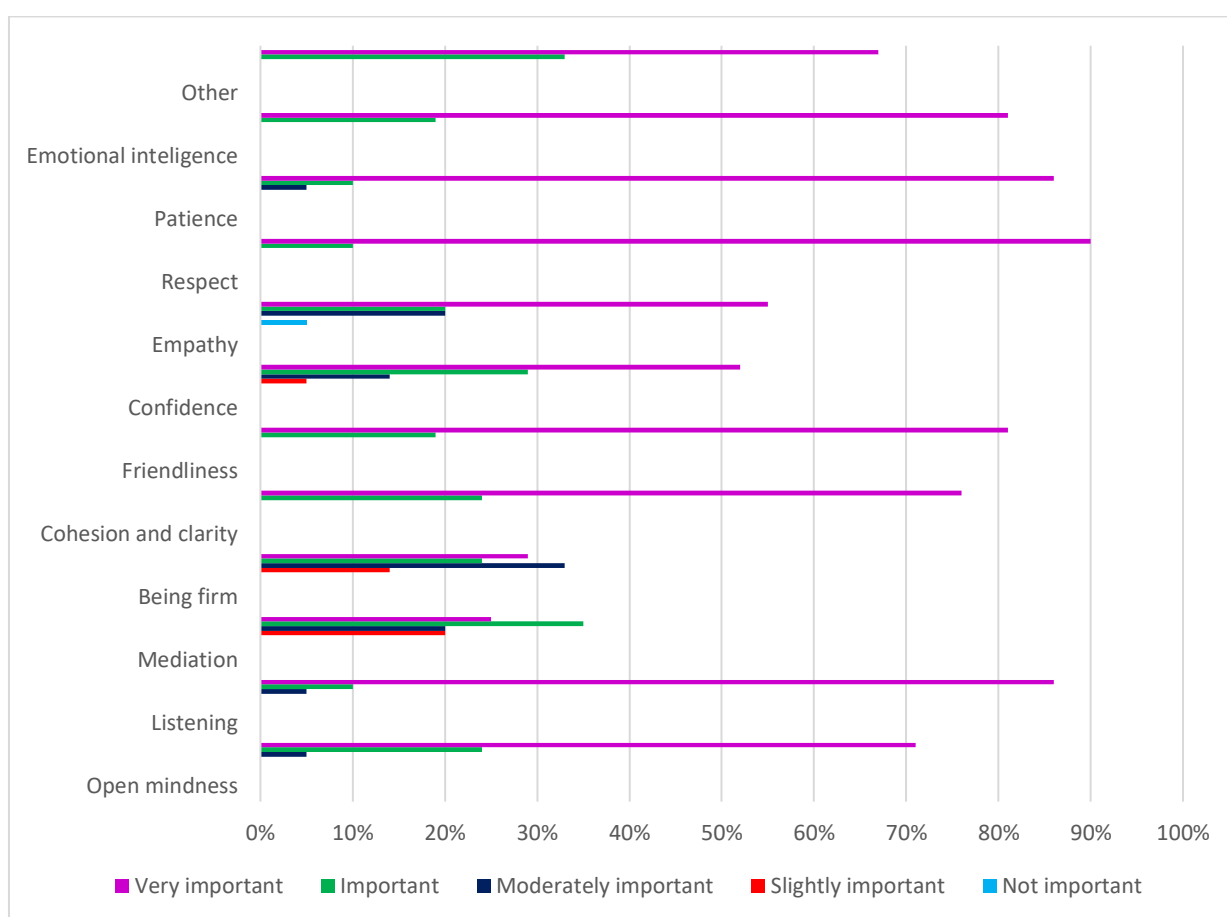
educators (3 participants) think that being firm is of small importance in communication with AFMIDs.

11. MEDIATION: 35% of educators (7 participants) that participated in the questionnaire think that mediation is important in communication with AFMIDs. 25% (5 participants) think that mediation is very important. 20% of educators (4 participants) think that mediation is of medium importance, and 20% think it is of small importance in communication with AFMIDs. One participant did not answer this particular feature.

12. Three participants selected the section "other". Among those two answers were given:

- Understanding
- Similar experience

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### Which are the problems you encounter in your lifelong learning activities? (n=19)

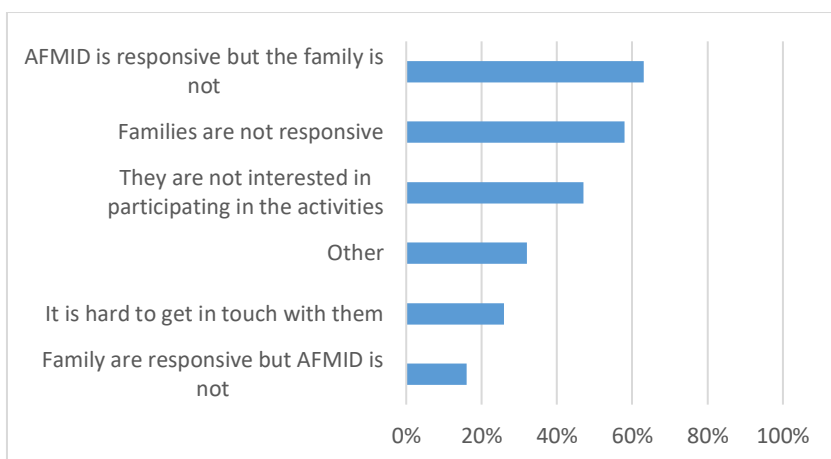
63% of educators (12 participants) that participated in the questionnaire work with families where AFMID is responsive, but the family is not. 58% of educators (11 participants) that participated in the questionnaire encounter non responsive families. 47% of educators (9 participants) deal with lack of interest in participation in activities. 26% of educators (5 participants) that participated in the questionnaire have problems with contacting the families with AFMID. 16% of educators (3 participants) work with responsive families,



where the AFMID is not responsive. In the section "other", 5 answers were given:

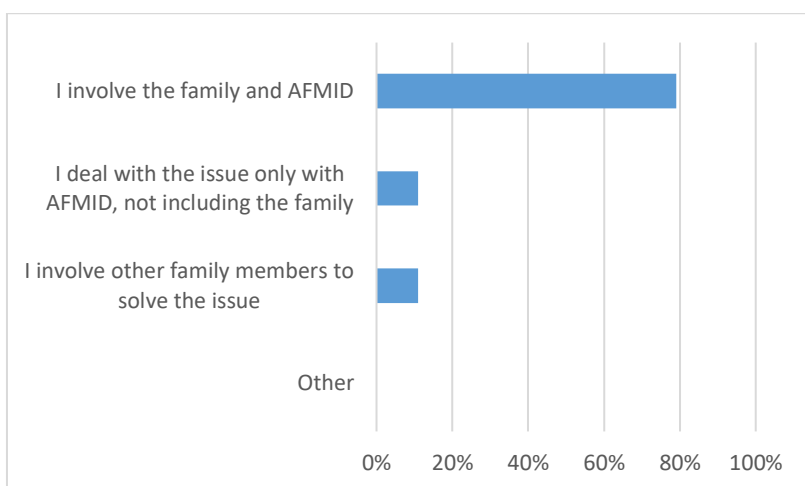
1. No major problems (2 participants)
2. Families lack in information about the programs
3. Especially non responsive young families
4. Aging of population – different interests
5. No problems in cooperation once you have gained the trust of families

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### How do you solve problems with AFMIDs (e.g. motivational, behavioural, emotional...) in the LL activities? (n=19)

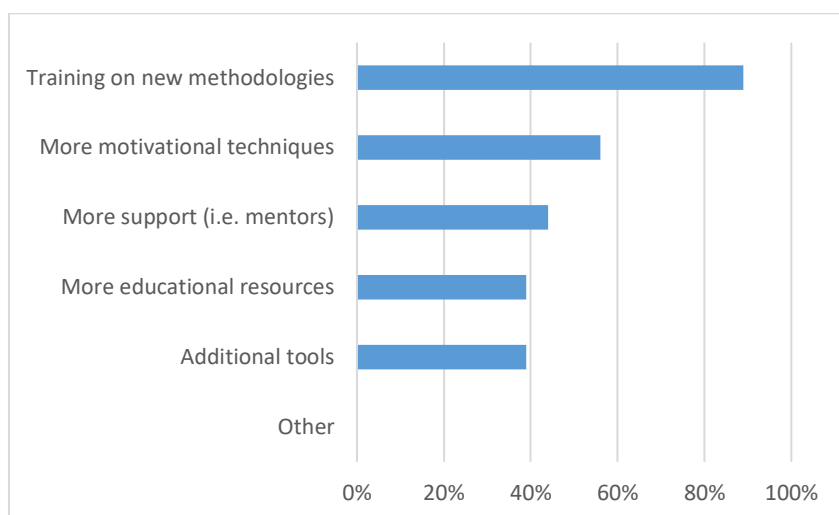
79% of educators (15 participants) that participated in the questionnaire include the whole family in solving problems. 11% of educators (2 participants) solve the problem only with AFMID, not including other members of the family. 11% of educators include other family members in solving the problem.



### As educator, what kind of support would help you improve your educational activities? (n=18)

89% of educators (16 participants) that participated in the questionnaire would appreciate training on new methodologies. 56% of educators (10 participants) would like to know more motivational techniques, 39% (7

participants) need more educational sources. 44% of educators (8 participants) would appreciate more mentorship support and 39% would need additional tools.



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### Which motivational techniques do you find useful when working with AFMID? (n=12)

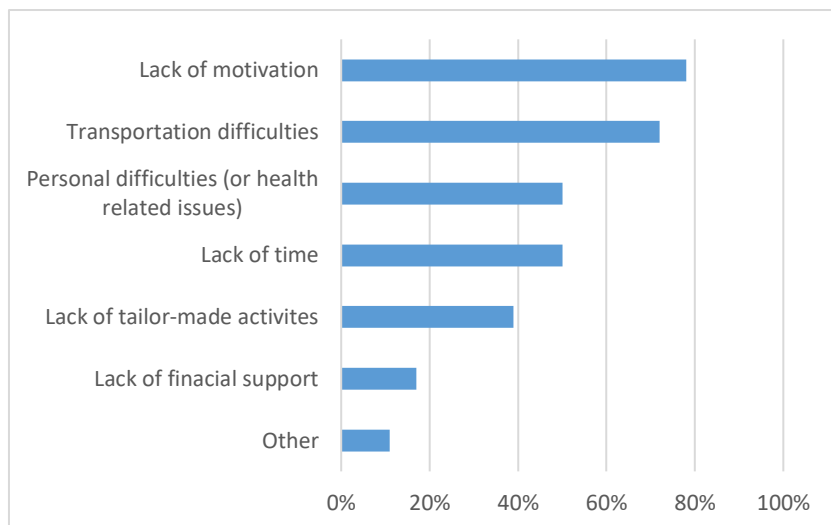
Ten answers were given:

1. Educator is actively engaged in activities with AFMID; implementing activities where progress is visible; playfulness and humorousness (2 participants)
2. Talking with families (2 participants)
3. Gaining trust from AFMIDs
4. Demonstration
5. Motivation is crucial, it has to come from the person with disabilities
6. Relaxing techniques
7. Positive and safe environment is very important for wellbeing of AFMID
8. Rewarding
9. Good company
10. Learning new things

### In your opinion, which are the reasons families with AFMIDs do not attend activities provided for them? (n=18)

78% of educators (14 participants) that participated in the questionnaire think that lack of motivation is the reason that families do not attend activities provided for them. 72% of educators (13 participants) think the reason is transport difficulties. 50% of educators (9 participants) think the reason for not attending activities is lack of time and personal issues (health etc.). 39% of educators (7 participants) think the reason is lack of activities, which are individually adapted. 11% (2 participants) replied "other", where two answers were given:

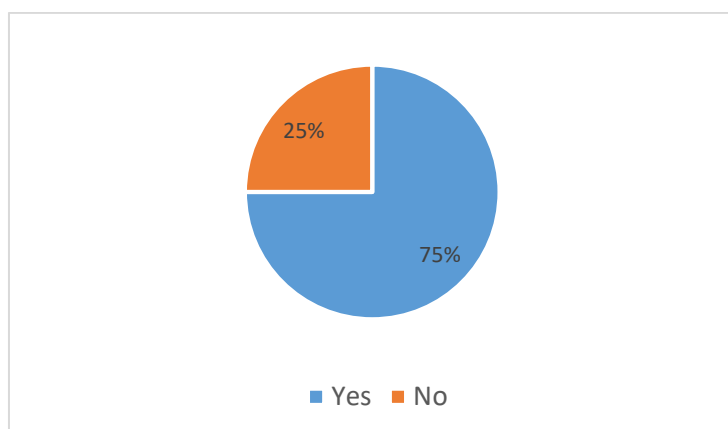
1. Families with AFMIDs are more likely to be isolated; they have difficulties connecting with other people and engaging in activities (especially in the beginning)
2. Parents are used to having their children at home, helping them with chores and everyday activities



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**Do you think if the activities were carried out in their home environment, AFMIDs and their families would be more likely to attend these activities? (n=16)**

75% of educators (12 participants) that participated in the questionnaire replied yes, 25% (4 participants) replied no.



**In your opinion, what is an effective communication strategy when working with families with AFMIDs? (n=16)**

Answers given:

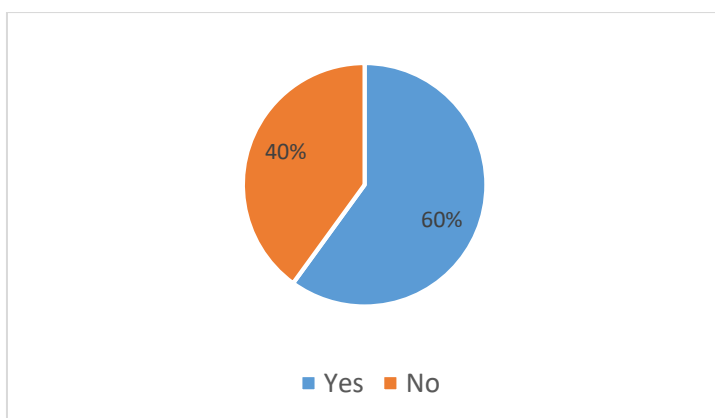
1. Personal contact and telephone (4 participants)
2. Socializing, talking (2 participants)
3. Non-invasive contact, socializing with people with common problems (2 participants)

4. Active listening, positive non-verbal communication (2 participants)
5. Positive attitude
6. Meetings, groups
7. Listening to families, making meaningful relations
8. Respectful attitude
9. It is important for families to be socially active; the best way to do that is to be included in LL programmes
10. To include AFMIDs and their families when planning LL activities

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**Do you think there is a risk of overburdening families with too much information on institutional forms of lifelong learning? (n=15)**

60% of educators (9 participants) that participated in the questionnaire replied yes, 40% (6 participants) replied no.



**If yes, what kind of content should be provided in communicating about LL activities with families? (n=8)**

Answers given:

1. Easy to read form of material (2 participants)
2. Content should be short and clear, everything in one place (2 participants)
3. Determining individual's interests
4. Age appropriate content (personal approach)
5. Help and support
6. Personal contact

**If no, how could overburdening be prevented? (n=5)**

Answers given:

1. Help and self-help groups (2 participants)
2. Families are satisfied if they have information they need at the moment
3. There is never too much information, families select what is useful for them
4. Gradually adding information (not everything at once)

**Based on your experience, do you have tips for implementing LL activities for families in their home environment? (n=12)**

Answers given:

1. Implementing activities which help families to integrate in unfamiliar environment (3 participants)
2. Small groups (2 participants)
3. Cooperation is crucial
4. You need proper space, volunteers, mentor/leader of activities and of course finance
5. Non formal socializing in small groups; LL implemented when the people in the group are acquainted with each other
6. Relaxation of families and AFMIDs
7. It is hard, because a lot of children do not want to leave home
8. Ask the families what they need; including them in planning of activities; adjust timing and content to their needs
9. Positive attitude

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**In your opinion, how important is a positive response and motivation from the environment when involving families with AFMID in LL programs? How would you promote it? (n=12)**

Answers given:

1. Very important; with personal, adapted approach, which is a response to their needs (3 participants)
2. All of this is important for families; promoting with achievements of existing programs
3. Very important; don't know how to promote it; big problem with deficit of volunteers
4. They are often included, because we provide free activities and transfer
5. Promoting by presenting the programmes, offered by associations
6. Personal contact
7. Active inclusion in environment outside home
8. Awareness and community care
9. Cooperation on every level is very important
10. The family needs time to accept their child with disabilities; then they need time to open up to others; at a later stage they are ready to join association and consequently join LL programmes

## 2.5 EDUCATOR QUESTIONNAIRE SUMMARY

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

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

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

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

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

## 2.6 FAMILY QUESTIONNAIRE ANALYSIS

The questionnaire was divided in two parts. The first part consisted of some general information about the family and the second part consisted of questions about LL activities answered by the family.

First, we wanted to know what educational activities do families with AFMID attend and how do they choose those activities. Second, we wanted to know how do the families get informed about LL activities and how they would prefer being informed.

Further, we wanted to know what problems do families encounter when engaged in LL activities and what kind of support would help their AFMID and the whole family during a learning activity.

Last, we wanted to know what are the learning needs of the AFMID and if the families are satisfied with the services from the institutions where AFMID is included (schools, Occupational Activity Centres, associations, etc.)



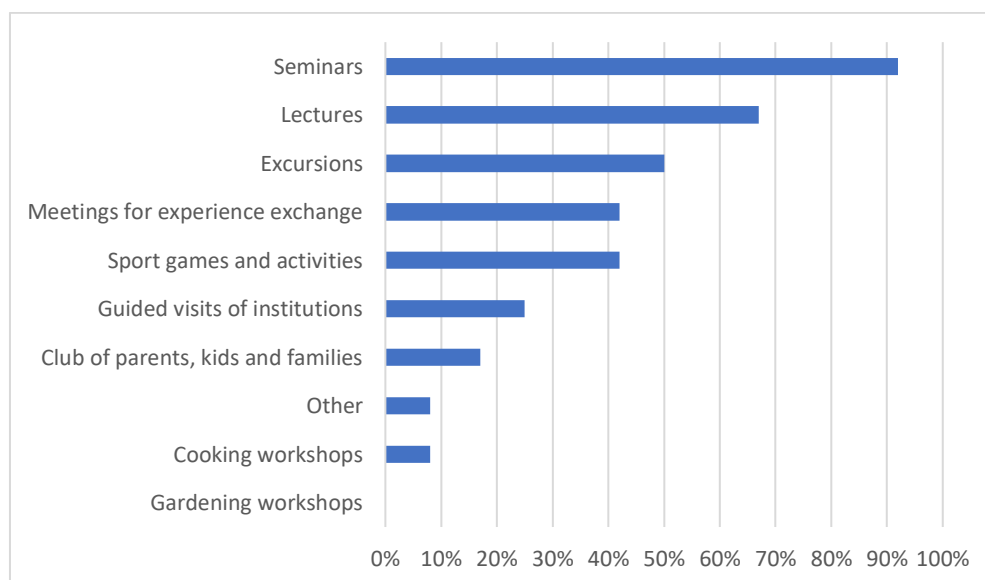
## How many people in your family are affected by intellectual disorders? (n=12)

All of the families that participated in the questionnaire have 1 family member with intellectual disability.

## Which educational activities does your family participate into in order to support your AFMID? (multiple answers possible) (n=12)

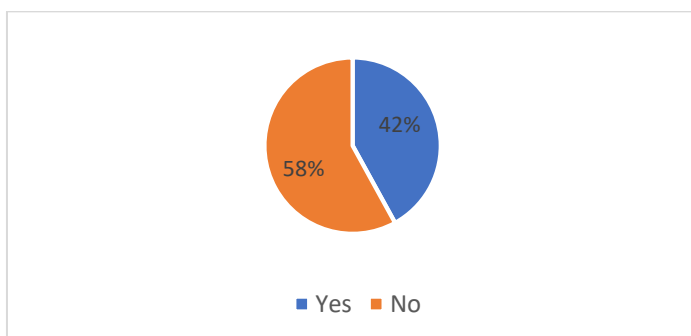
All of the families that participated in the questionnaire participate in weekend seminars in order to support their AFMID. 92% (11 families) participate in seminars, 67% (8 families) participate in lectures. 50% of the families that participated in the questionnaire (6 families) attend excursions in order to support their AFMID. 42% of the families that participated in the questionnaire (5 families) attend sport games and activities, also 42% attend meetings for experience exchange among families. 25% of the families that participated in the questionnaire (3 families) attend guided visits of institutions, 17% (2 families) participate in club of parents, kids and families. 8% of the families that participated in the questionnaire (1 family) attends cooking workshops. None of the families attend gardening workshops. 1 family (8%) replied "other" and the answer was:

- The four-year cycle



## Do you meet with educators who implement activities for AFMID before the start of them? (n=12)

58% of the families that participated in the questionnaire (7 families) meet with the educators who implement LL activities for AFMID before the start of them, 42% (5 families) do not.



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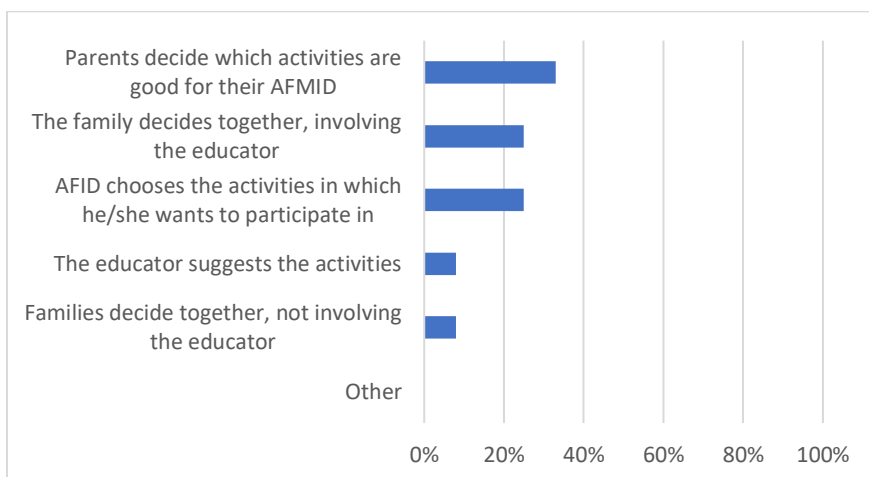
## If yes, how often? (n=3)

Three answers were given:

1. Up to 2 times
2. On occasion
3. Several times

## How are these activities chosen? (n=12)

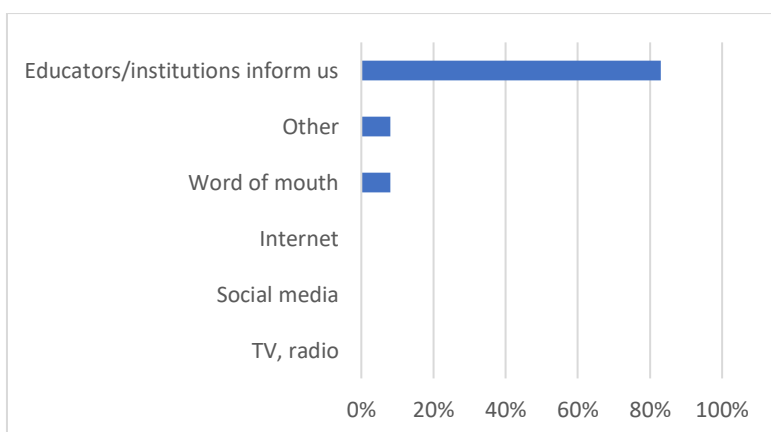
In 33% of the families that participated in the questionnaire (4 families) the parents decide which activities are good for their AFMID. 25% of the families (3 families) decide together including the educator. In 25% of the families that participated in the questionnaire (3 families) the AFMID decides in which activity he/she would like to participate. In 8% of the families that participated in the questionnaire (1 family) the educator recommends the activity that would be appropriate for the AFMID. 8% of the families decide together for the activity not including the educator.



## How do you get informed on learning and educational activities for your family? (n=12)

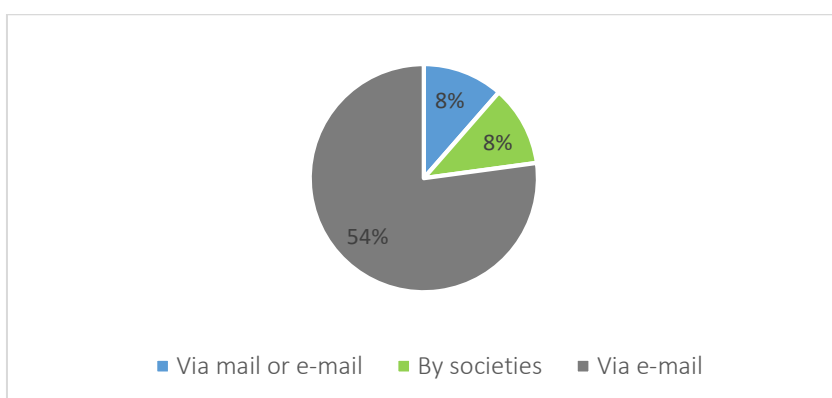
83% of the families that participated in the questionnaire (10 families) are informed about learning and educational activities from the educators and institutions. 8% of the families (1 family) get the information from other people (word of mouth). None of the families that participated in the questionnaire chose the answers: internet, social media and TV/radio. 8% of the families that participated in the questionnaire replied "other" and the answer was:

- All of the above



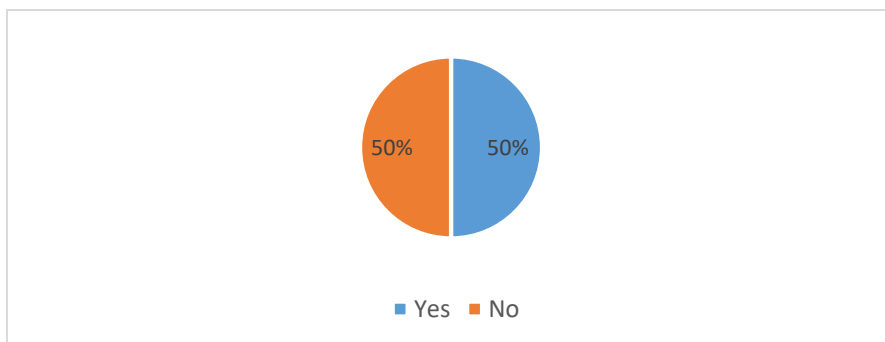
## How would you prefer being contacted by institutions and educators on LL activities? (n=9)

54% of the families that participated in the questionnaire (7 participants) would like to be contacted via e-mail. 8% would like to be contacted via regular mail or e-mail. 8% of the families that participated in the questionnaire (1 participant) would like to be contacted via local societies.



## Do you think public services advertise their opportunities with the right communication channels? (n=12)

50% of the families that participated in the questionnaire (6 participants) replied yes and 50% replied no.



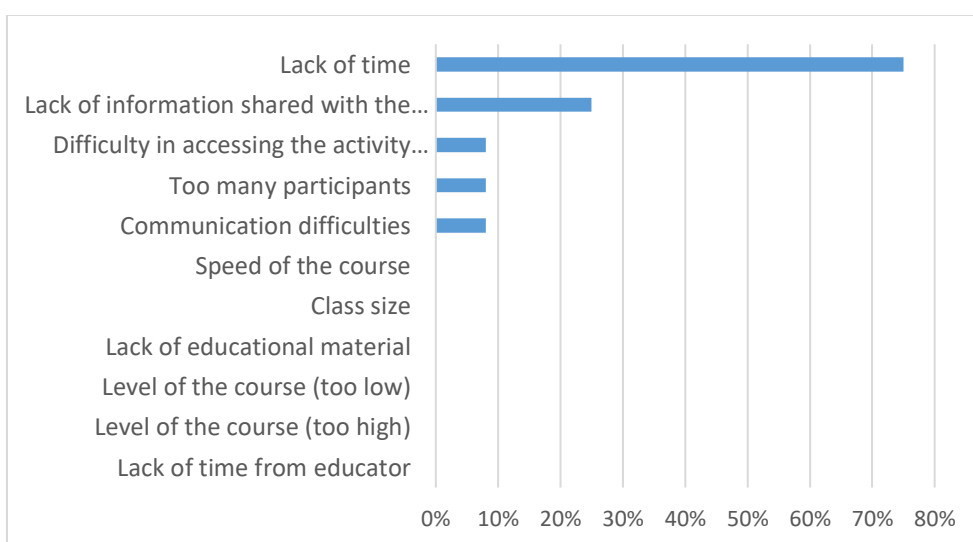
### Do you experience problems when engaged in LL activities? (n=12)

75% of the families that participated in the questionnaire (9 participants) say they have problems engaging in LL activities due to lack of time. 25% (3 participants) say the problem is lack of information shared with the educators. 8% (1 participant) say they have difficulties in accessing the activity financially. 8% say the problem is that there are too many participants in LL activities; and also 8% say they have communication difficulties. 17% (2 participants) replied "other" and the answers were:

1. No problems
2. Lack of offered activities

There were other answers available, but none of the participants chose them:

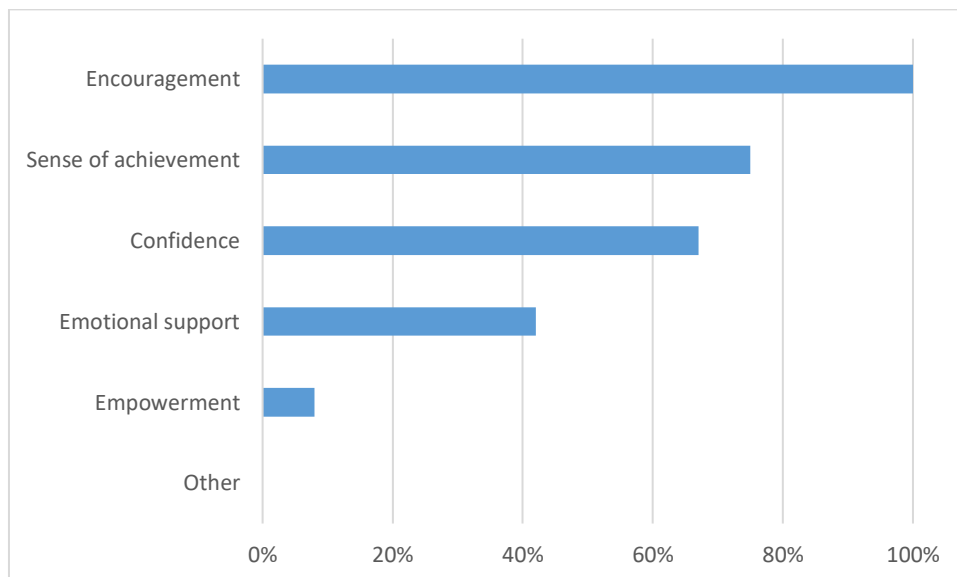
- Lack of educational material
- Class size
- Speed of the course
- Lack of time from educator
- Level of the course (too high)
- Level of the course (too low)



### What do AFMID need from a personal point of view during a learning activity? (n=12)

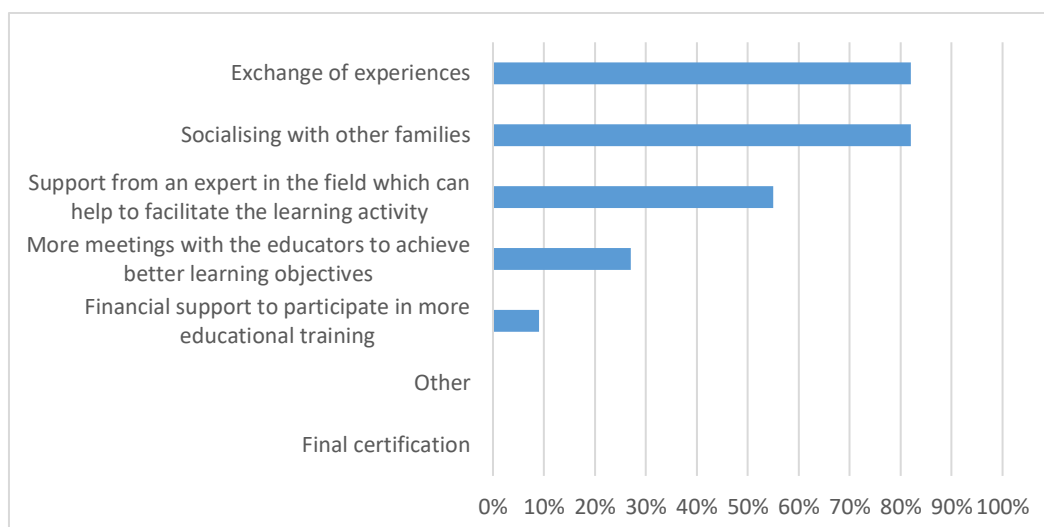
All of the families that participated in the questionnaire (12 participants) say that AFMID needs encouragement during a learning activity. 75% (9 participants) say that AFMID needs sense of achievement, 67% say they need confidence and 42% (5 participants) say they need emotional support. 8% of the families that participated in the questionnaire (1 participant) say AFMID needs empowerment during a learning activity.

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### What kind of support would improve the educational activities your family participates in? (n=11)

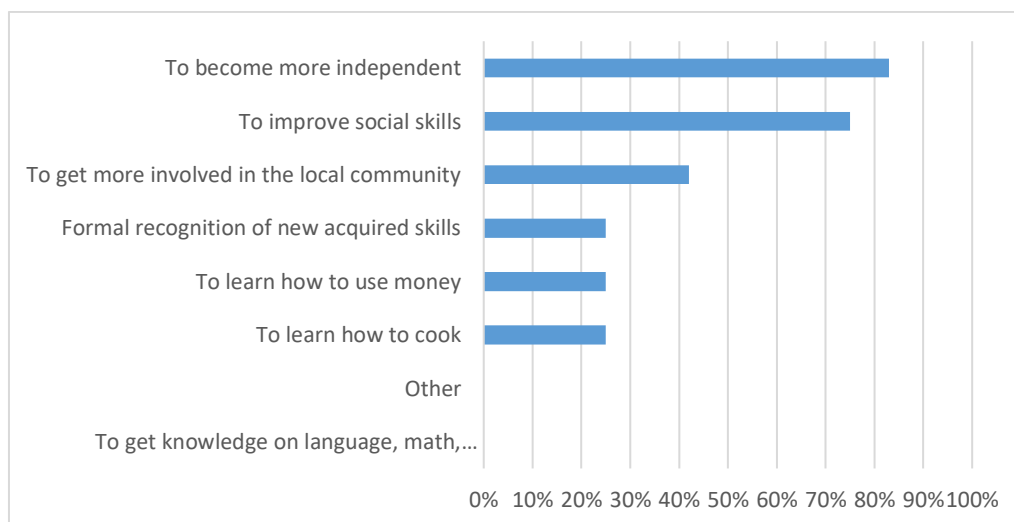
82% of the families that participated in the questionnaire (9 participants) say that socializing with other families would improve the educational activities. Also 82% say that exchange of experiences would be the support that improves the educational activities. 55% (6 participants) would like the support of an expert in the field which can help to facilitate the learning activity. 27% (3 participants) would like more meetings with the educators to achieve better learning objectives. 9% would like financial support to participate in more educational training. None of the families that participated in the questionnaire selected the option "final certification" and "other".



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### What are the learning needs to the concerned members of your family? (n=12)

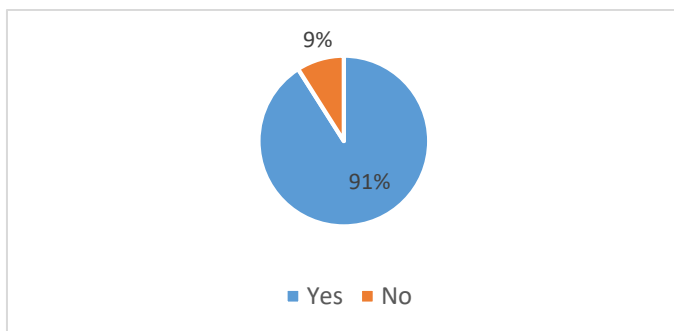
83% of the families that participated in the questionnaire (10 participants) say that becoming more independent is what AFMID needs. 75% (9 participants) say that AFMID need is to improve their social skills. 42% (5 participants) say that AFMID need is to get more involved in local community. 25% (3 participants) say that the learning needs of AFMID is to learn how to cook, to learn how to use money and to get formal recognition of new acquired skills. None of the families that participated in the questionnaire selected options "other" and "to get knowledge on language, math, science through informal activities".



### Are you satisfied with the services you get from the institutions where your AFMID is included (school, group home, associations etc.)? (n=11)

91% of the families that participated in the questionnaire are satisfied with the services from institutions, 9% are not.





## 2.6 FAMILY QUESTIONNAIRE SUMMARY

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

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

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

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

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

### 3 NATIONAL REPORT ITALY

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

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#### 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).

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Students with disabilities can also:

1. have more time to do verification tests or do them in ways other than their companions;
2. follow personalized programmes, even different from those of the companions;
3. make verification tests different from those of the companions: equivalent tests or differentiated tests.

### 3.3 Lifelong learning for persons with intellectual disabilities

With regard to the possibility of orientation and professional training for people with mental disabilities, the Italian situation is complex, differentiated and often unsatisfactory. In a reality better than the current one, adolescents with intellectual disabilities after middle school should have the possibility of attending professional schools with staff resources and with adequate teachers to promote the integration of people with mental retardation. Often this does not happen and they are enrolled in other schools (including scientific or classical high schools).

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

Taking note of this widespread lack, it must however be emphasized that since the years around 1970 Italy has favoured experiences of orientation, professional qualification and cutting-edge work placement (Montobbio and Casapietra, 1982; Neri and Brotini, 1982; Ravaccia, 1982, Bolpin, Schena and Zeffiro, 1986, Barbieri, D'Angelo, Oriani and Palmonari, 1987, Bonaconsa, Fattorelli, Fichera and Schena, 1988, Montobbio, 1982, 1985, 1989, 1999, Moderato and Paltrinieri, 1989; Moniga and Vianello, 1994, 1996; Causin and De Pieri, 1999; Breda, 2001; Cassullo, 2001; Mainardi, 2001; Vianello, 2006).

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

Until the sixties, however, the regulations on the subject did not provide for interventions in favour of people with disabilities. With the L. n. 118/71 the first indications are given and, then, with the L. n. 845/78, more specific provisions in this regard, such as the coherence between the vocational training system and the general education system, the professional qualification of the disabled and the disabled, the interventions necessary to ensure them the right to vocational training, direct training initiatives to the professional 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.

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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.

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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.

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### 3.5 Questionnaires analysis

Different questionnaires have been deployed both to educators and families with AFMID.

- The first questionnaire was filled out by 20 educators. It aimed at casting light on the motivational support methods carried out by educators in order to involve and interact with families and their adult family members with intellectual disorders.

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

- The family questionnaire was completed by 10 respondents.

The questionnaire was divided into two parts; first part consisted of some general information on the family, second part consisted of 11 closed questions that were answered within the whole family.

With the questionnaire, we first wanted to find out what kind of activities the families and AFMID attend. Second, we wanted to find out how they get in contact with educators and what are the reasons they attend some activities rather than others. Focusing on decision making process, emphasize was on finding out how the family identify and thus decide to attend these activities together with their AFMID. We wanted to find out if



the families believe they would benefit from this kind of activities (gardening and cooking) and in which way.

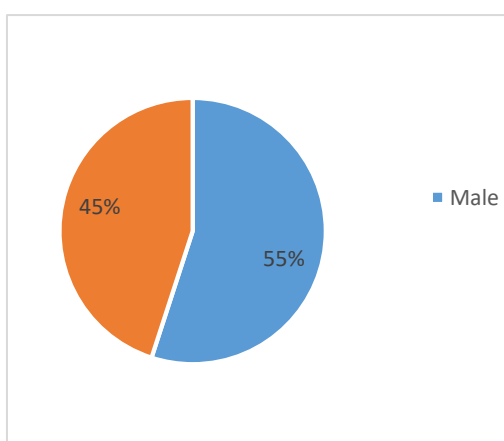
## QUESTIONNAIRE FOR EDUCATORS

### PART 1: GENERAL INFORMATION ABOUT THE EDUCATORS

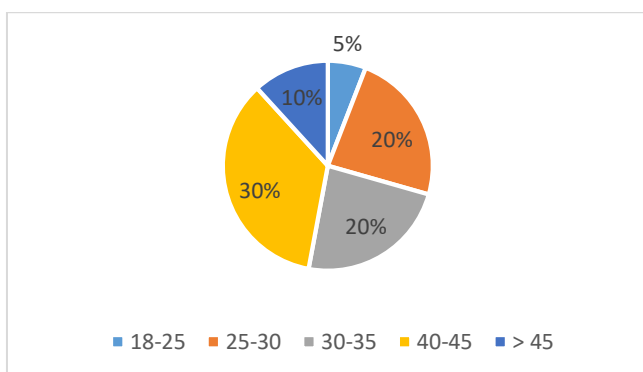
**Age and gender of educators:** Between the age of 18 and 45, the educators that participated in the questionnaire were mainly men (55%), while women represent the 45% of the group. With regard to age, the most represented group is the 40-45 category (30%), followed by 35-40 and 25-30 segments (both 20%).

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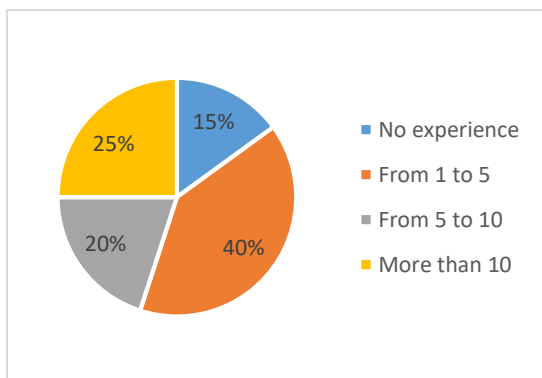
#### Are you?



#### How old are you?

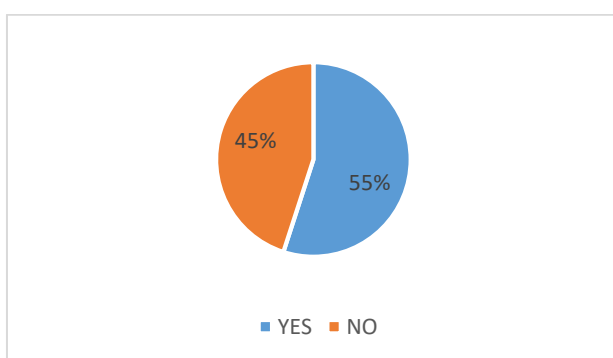


**How many years of experience (formal and non-formal) do you have working with families with AFMID?**



## PART 2: QUESTIONS FOR EDUCATORS

### Q1: Is it easy to get in touch with families with AMFID?

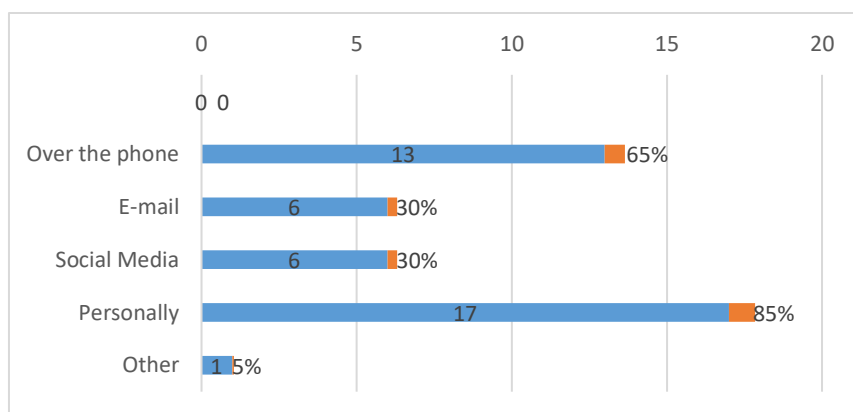


Even if the vast majority answered that it is easy to get in touch with families with AMFID, 45% of educators faced difficulties in contacting these families.

#### Q1.1: If no, what are the main obstacles in this communication? (open question)

- Adoption of a complex, unclear and invasive communication.
- Mistrust – Lack of social networks.
- Educative divergences. Families resist to change and strive to preserve the *status quo*.
- Misinformation, ignorance, suspiciousness, socio-economic hardship.
- Do not want to communicate, unable to ask for help, fear of being misunderstood.
- Fear of being judged.
- Distrust, closed to the outside world.
- Do not use social media.

**Q2: Which are the main channels of communication do you use with families with AFMID?**



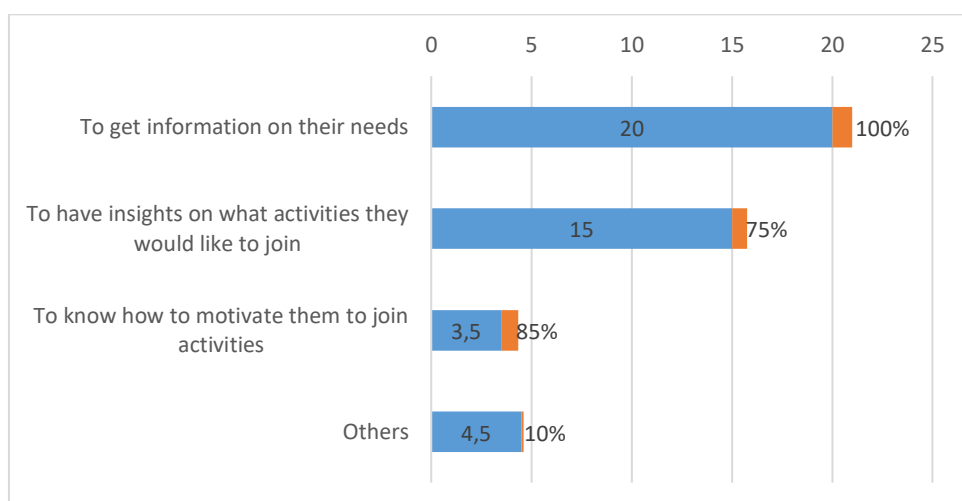
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85% of the educators prefer to contact personally families with AFMID. It is worth noting that few of them use e-mail or/and social media to communicate with these families.

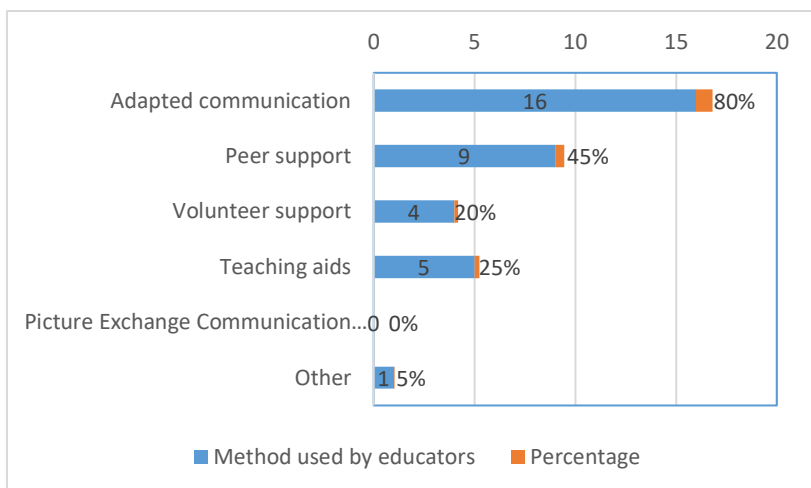
**Q3: When AFMID is included in your organization, do you perform any kind of meeting / interview / conversation with him/her family to determine their educational need/preference?**



**Q3.1: If yes, why do you think it's useful? You can select multiple options**

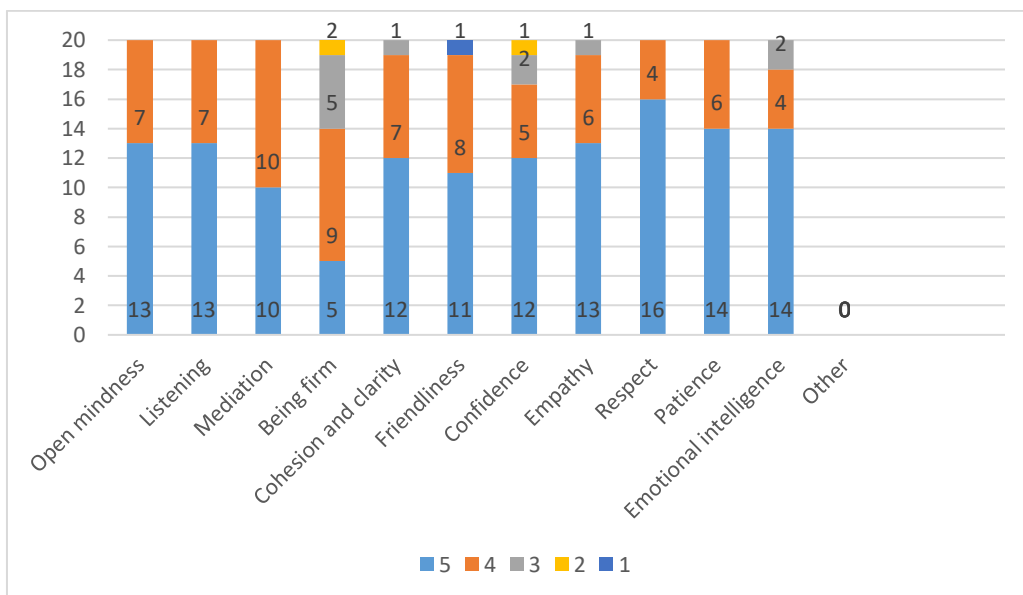


**Q4: What kind of methods do you use in your activities for get AFMID involved?**



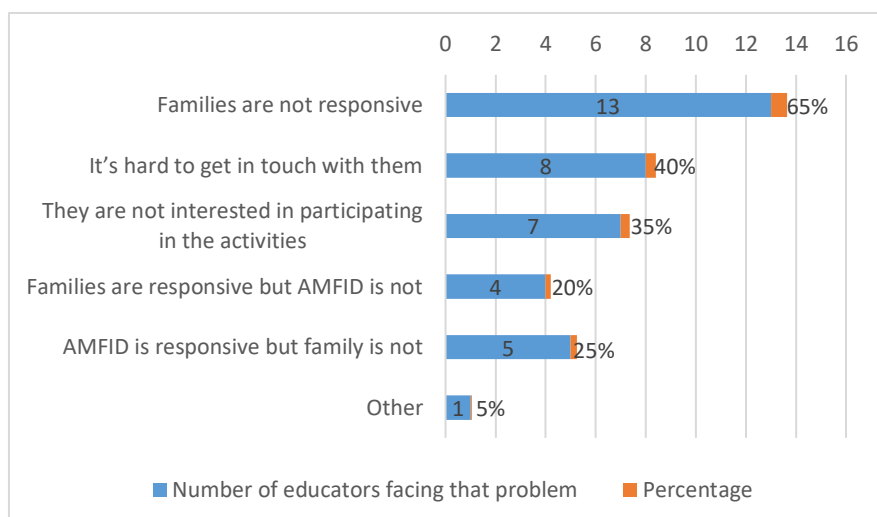
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**Q5: What kind of features in the communication process with AFMID do you think an educator should have to successfully work with them? (multiple choices possible) – scaled questions (1/5)**



Most common answers were “respect”, “patience”, “open mindness” and “listening” and were evaluated between 5 and 4 (Likert scale 1/5).

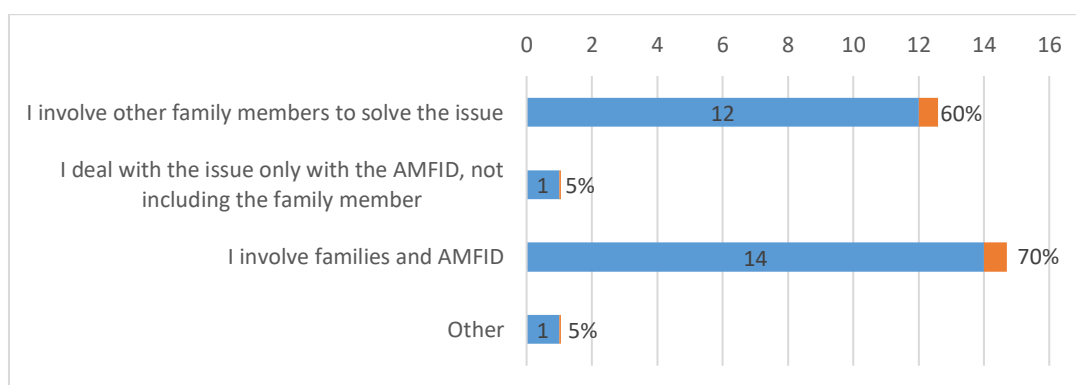
**Q6: Do you experience problems while you implement lifelong learning activities? Which problems do you meet when you work with them?**



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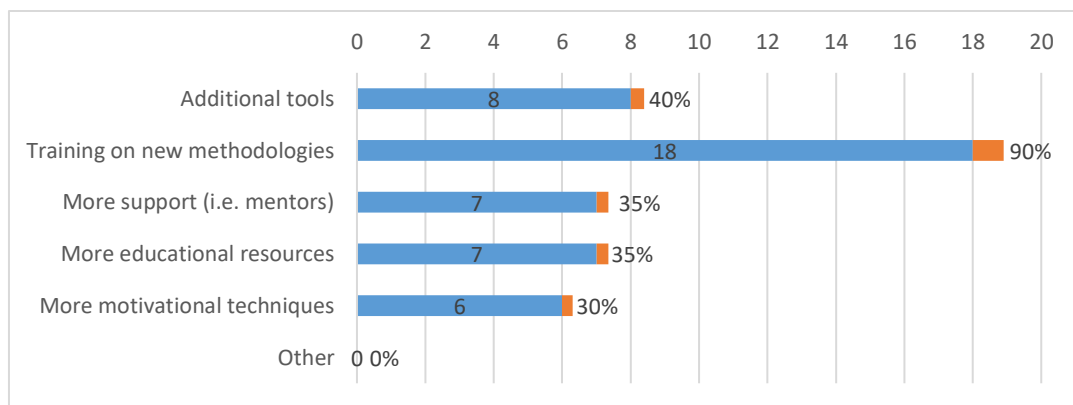
According to 65% of the educators, families are not responsive and this constitutes an obstacle to LL activities. Furthermore, educators had difficulties getting in touch with families (40%) and experimented a lack of interest in participating to LL activities (35%).

**Q7: How do you engage to resolve problems (e.g. motivational, behavioural, emotional) of the AFMID when they're engaged in lifelong learning activities?**



In the first place, respondents revealed that they prefer to involve families and AMFID (70%). 60% of educators involve other family members in order to solve the issue. Only one of the educators interviewed not include family members when resolving a problem of the AFMID.

**Q8: As educator, what kind of support would help you to improve during the educational activities that you deliver?**



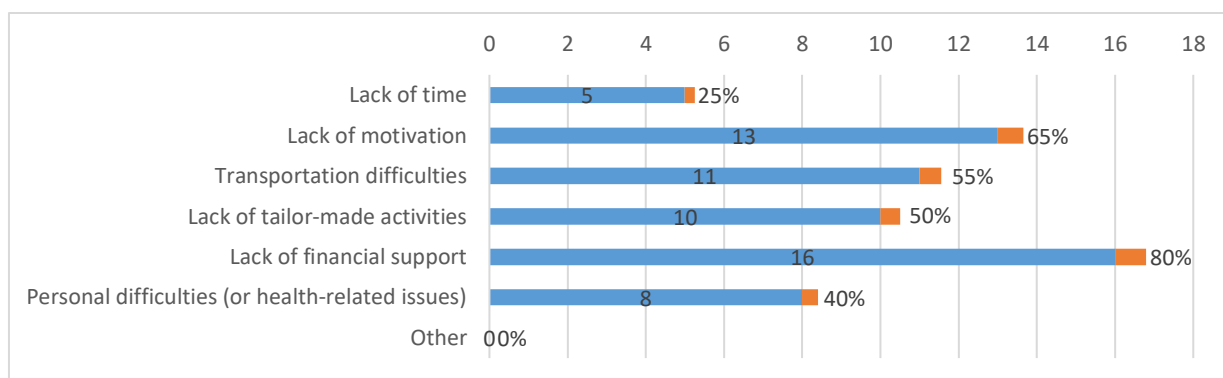
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The vast majority (18 educators) answered that a training on new methodologies would help him/her to improve during the educational activities delivered. 40% of educators interviewed would prefer additional tools while 35% of them would opt for more support or more educational resources.

**Q8bis: Which motivational techniques do you find effective when working with AFMID?**

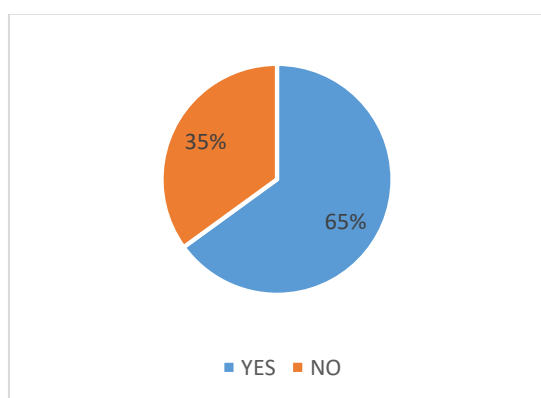
- Do not cause adverse reactions which also affect the formulation of a simple question.
- Make them feel guided and protected (from their own fear and from the ones created by the interlocutors.)
- Involvement in manual activities such as crafting and/or gardening.
- Peer support
- Positive and negative reinforcement. Token economy. Choose exciting activities.
- Understand the needs.
- Positive reinforcement.
- Token.
- Art-therapy.
- Strengthen the behavioural aspects which are intended to enhance.
- Contacts and interpersonal relationships.
- Autonomy.
- Work on self-confidence.
- Involvement starting from the needs and desires of the subjects.
- Peer-to-peer assistance
- Create a debate with other families.
- Show videos from previous activities implemented by other AMFID.

**Q9: Which are the reasons, in your opinion, that the AFMID and families are not included in activities provided for them:**



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**Q10: Do you think that if the activities were carried out in the home environment, the AFMID and families would be more keen to practice the activities?**



65% of educators think that if the activities were carried out in the home environment, the AFMID and families would be more keen to practice the activities. By contrast, 35% of the educators interviewed responded negatively to the above-mentioned question.

**Q11: What is in your opinion an effective communication strategy when you work with families with AFMID?**

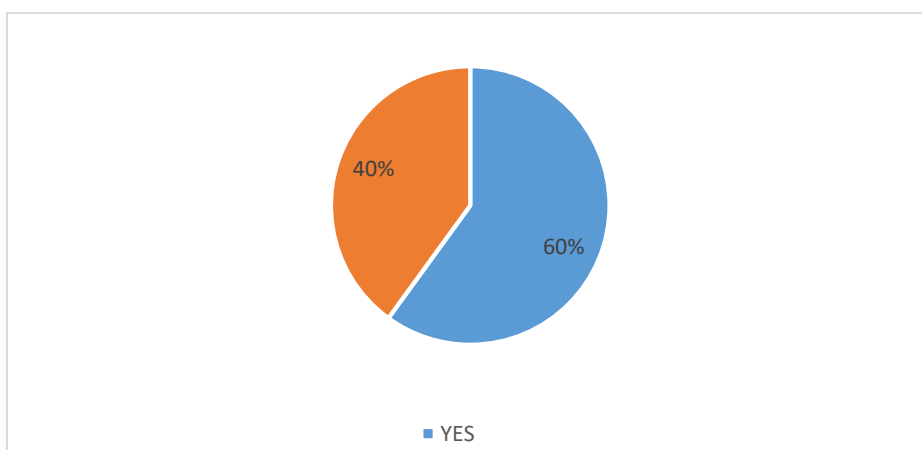
- Direct communication.
- Give families the chance to believe that the educator has solutions to propose beyond the AFMID's disability.
- Involvement in information seminars on new legislation in the sector and in particular on the resulting benefits.
- Phone calling, face-to-face.
- Private and group interviews.
- Understand the needs.
- Be clear, simple, empathetic, cordial, but well structured.
- ....



- Meeting economic needs by offering more activities at a lower cost, taking into consideration AFMID's interests and those sectors in which he has to improve his ability.
- Active listening.
- Empathy, Listening.
- Great empathy and predisposition to communication.
- Be clear.
- I do not know.
- Direct communication.
- Social media, email.
- Cross media (magazines, social media, personal contact)
- Put them in contact with other families
- Video and photos of previous workshop.

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**Q12: Do you think there is a risk of overburdening families with too much information on institutional forms of lifelong learning?**



**If no, how can it be prevented?**

- Training the parents on the method used in order to better understand possible developments and the potential problem may arise during the LL process.
- Provide brief and clear information to the families.
- Involving the families and let them participate actively.

**Q12.bis: If yes, what kind of content should be provided in communicating about LL activities to families?**

- Descriptive contents to highlight the concreteness and tangibility of the LL activities.
- No contents. Understand the needs.
- Catchy and very precise material.
- I don't know.

**Q13: Based on your experience, do you have tips for implementing LL activities for families in their own home environment?**

- No
- Giving a role to all members of the family. The family play an active role within a context where everyone performs a specific task, complementary to the others.
- Keep on doing at home the activities performed within a territorial project.
- Doing activities they can easily perform at home.
- Establish a preliminary relationship of trust and openness.
- Understanding the environment without judging it.
- I don't know.
- Carry out/implementing group work
- I don't know.
- Have more time to implement LL activities.
- First, work with the kid and then explain the activities to the parents in order to ensure continuity.
- Households should be guided and accompanied, at least during the first period.
- Do activities closer to AFMID's interests
- Do gardening, cooking and tailoring.
- Do gardening, cooking and physical activity.
- Involve the families to better understand which are the most useful activities for the AFMID.
- Greater variety of activities.

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**Q14: How much is it important a positive response and motivation from the environment when involving families of vulnerable adults in lifelong learning programmes? How would you promote it?**

- The activity to be proposed should be integrated into a wider programme involving the whole social context within which such activity will be carried out.
- It is very important to prevent and tackle isolation. Promoting a constant dialogue between those who are already in permanent learning programmes and who could potentially participate.
- Very Important.
- I would promote it within the associative networks to which family members and users already belong
- Very important.
- Very important. Not just me but with everyone's contributions.
- Act locally, involving the community.

- Fundamental, because educational paths must be parallel and not conflicting. It is very important to collaborate with families and to agree on the educational programme and objectives.
- Fundamental.
- Involving the families and informing them on the main goals and the process to be followed.
- Greater involvement of families.
- Very important. I would promote it with the aid of videos on the activities carried out with the adult.
- Very important
- With periodic meetings with operators but above all organizing meetings between family members who live similar dynamics.
- Fundamental.
- Direct dialogue.
- Direct dialogue.
- Very Important.
- It is very important motivation to promote with peer-to-peer activities.
- Very important.

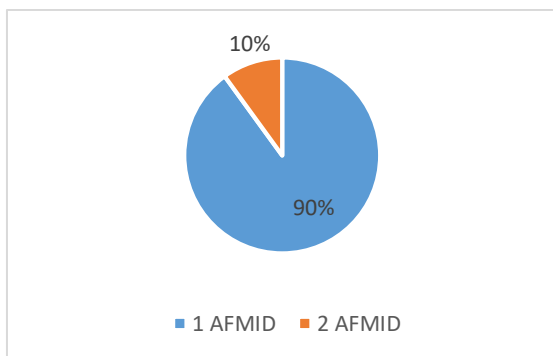
### 3.6 Educators questionnaire summary

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

## QUESTIONNAIRE FOR THE FAMILIES

### PART 1: GENERAL INFORMATION ABOUT THE FAMILIES

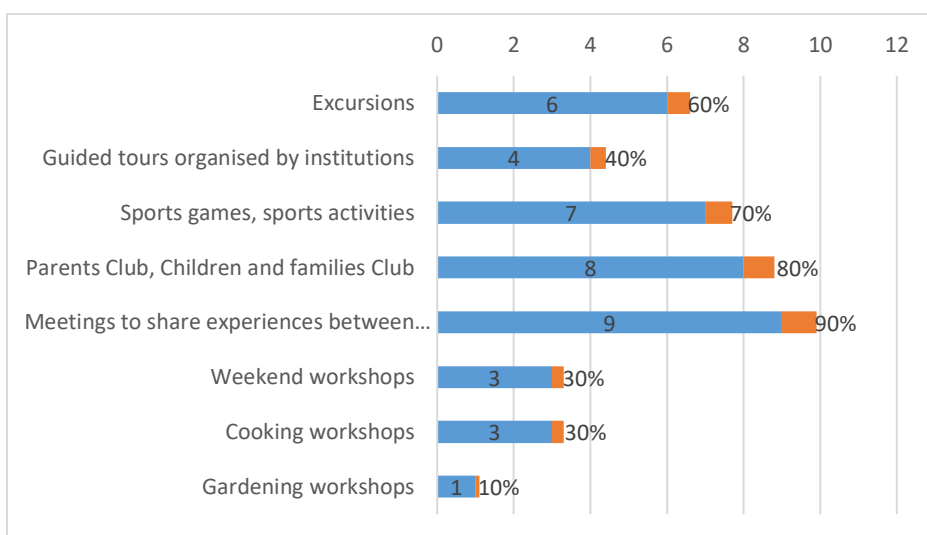
**How many people in your family are affected by intellectual disorders?**



9 families out of 10 have one AFMID within their household.

## PART 2: QUESTIONS FOR THE WHOLE FAMILY

**Q1: Which educational activities does your family participate into in order to support your AFMID?**

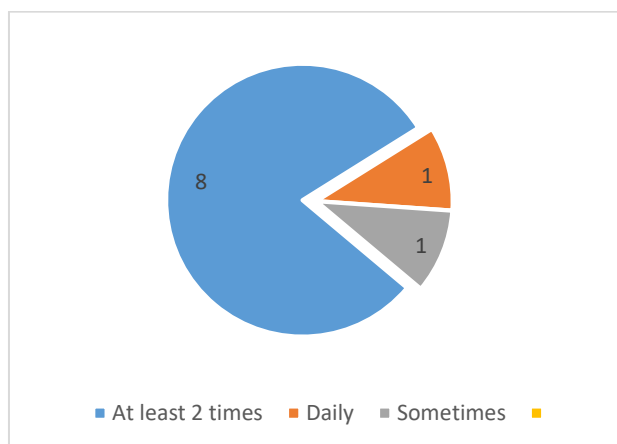


**Q2: Do you meet with educators who implement activities for AFMID before the start of them?**



The absolute majority of families (100 % of the total of the respondents) meet the educators before the start of the educational activities.

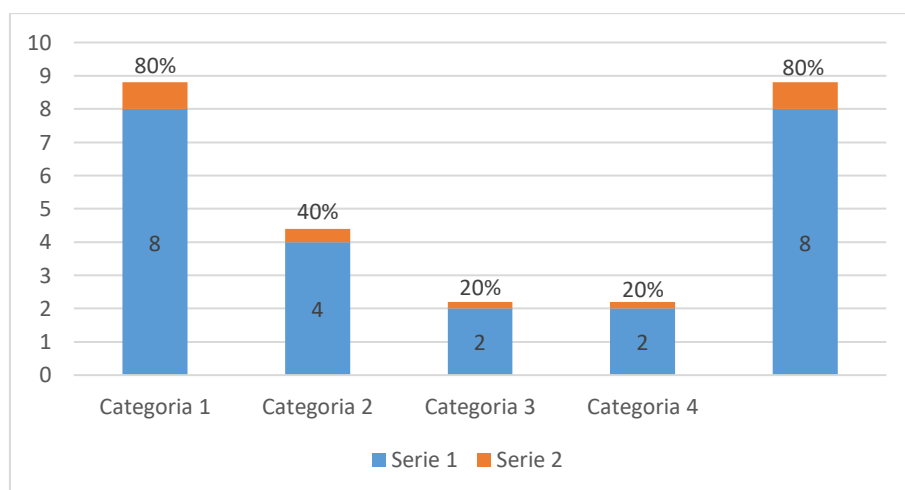
### Q 2.1: How often?



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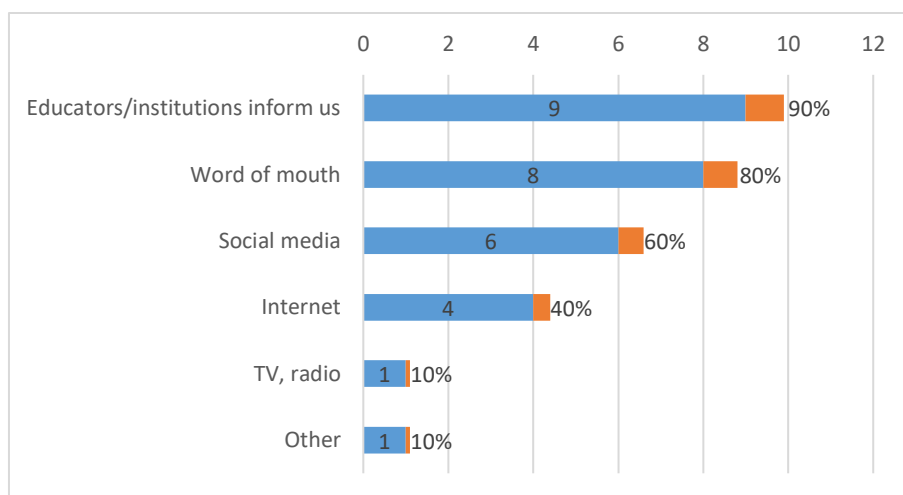
The majority of the families interviewed (8 families out of 10) answered that they meet the educators at least 2 times before the beginning of the educational activities. Only one family meets the educators on a daily basis.

### Q.3: How these educational activities are chosen?



Parents decide together with the educators or the AFMID takes a decision on this matter. According to the answers given by the respondents, it is worth noting that rarely the educational activities are chosen by the parents, excluding the AFMID or the educators.

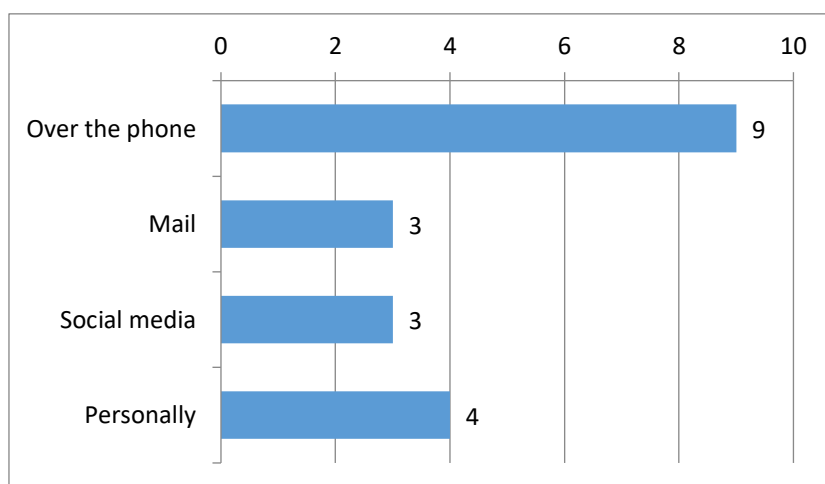
#### Q4: How do you get informed on learning and educational activities for your family?



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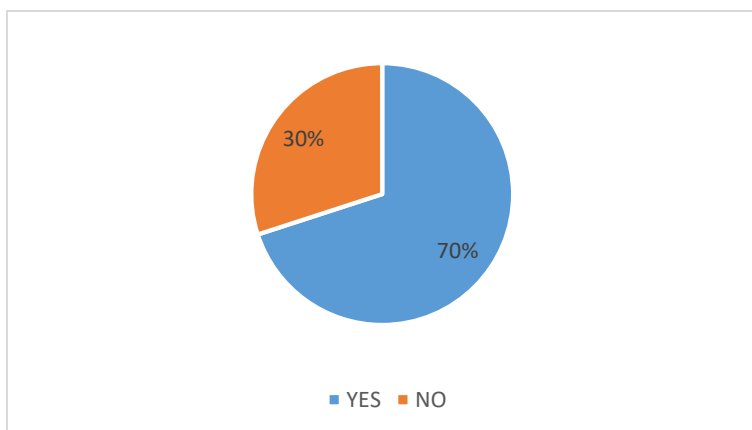
90 % of families have been informed by the institutions or by the educators. The 80% answered that they get informed through word of mouth while 60% thanks to social media.

#### Q4bis: How would you prefer being contacted by institutions and educators on LL activities?



In 10 cases (90 % of the total of the respondents), the families answered that they prefer being contacted by phone. 4 families answered that they prefer being informed personally.

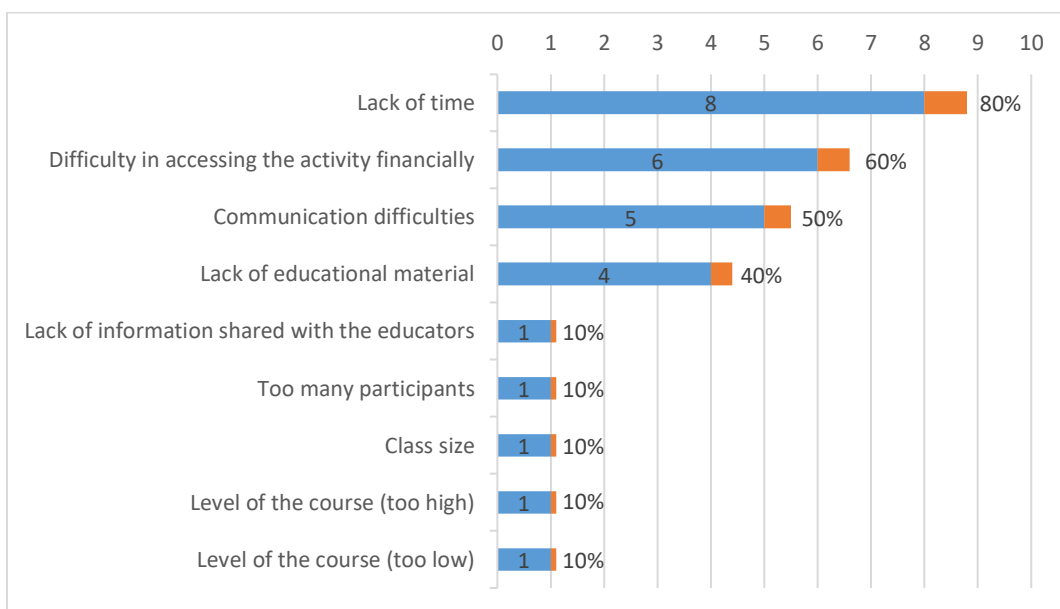
**Q5: Do you think public services advertise their opportunities with the right communication channels?**



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70% of families think that the communication channels used by the public services are appropriate.

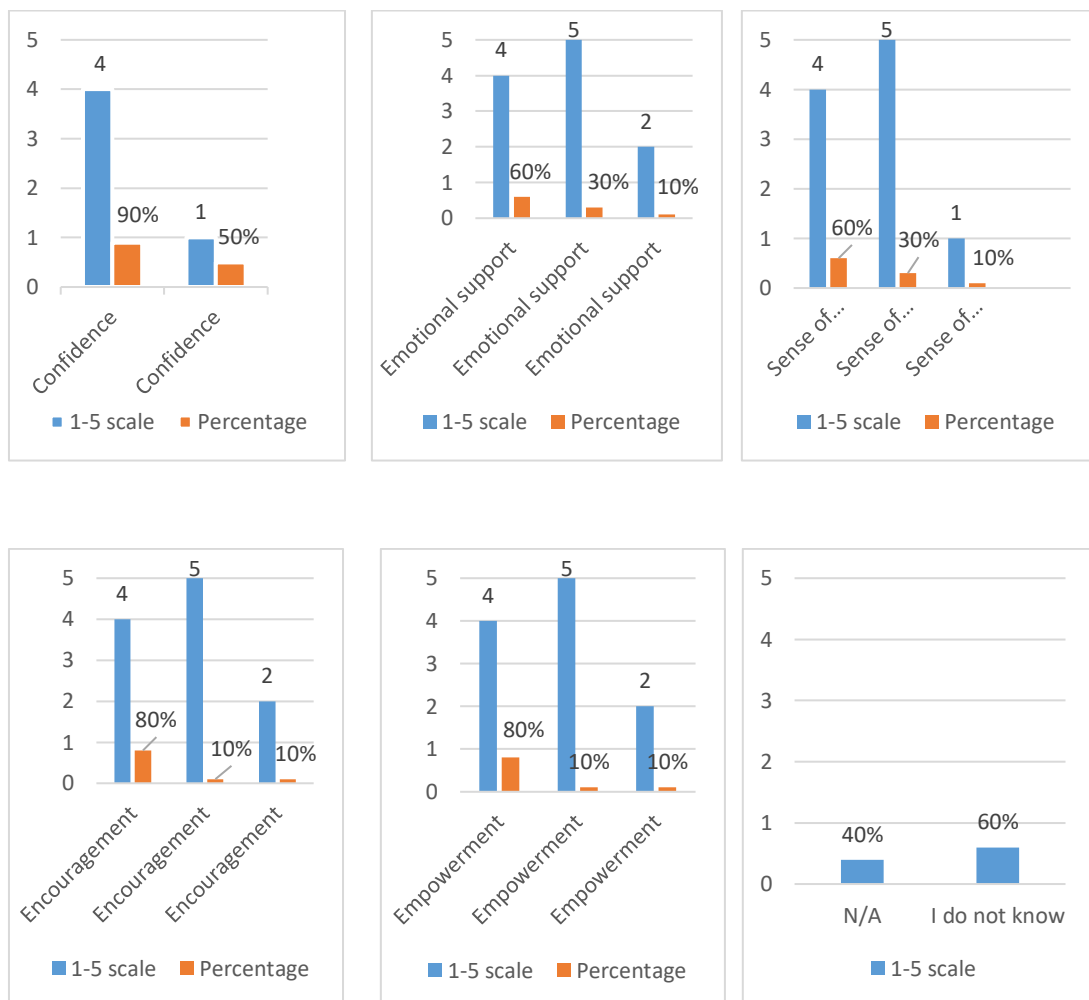
**Q6 Do you experience problems when engaged in lifelong learning activities? Can you describe the problems you meet? You can select multiple options:**



Lack of time represents the biggest problem for families engaged in LL activities (80%). 60% of them faced financial difficulties in accessing these activities while respectively 50% and 40% had communication difficulties and lacked of educational material.

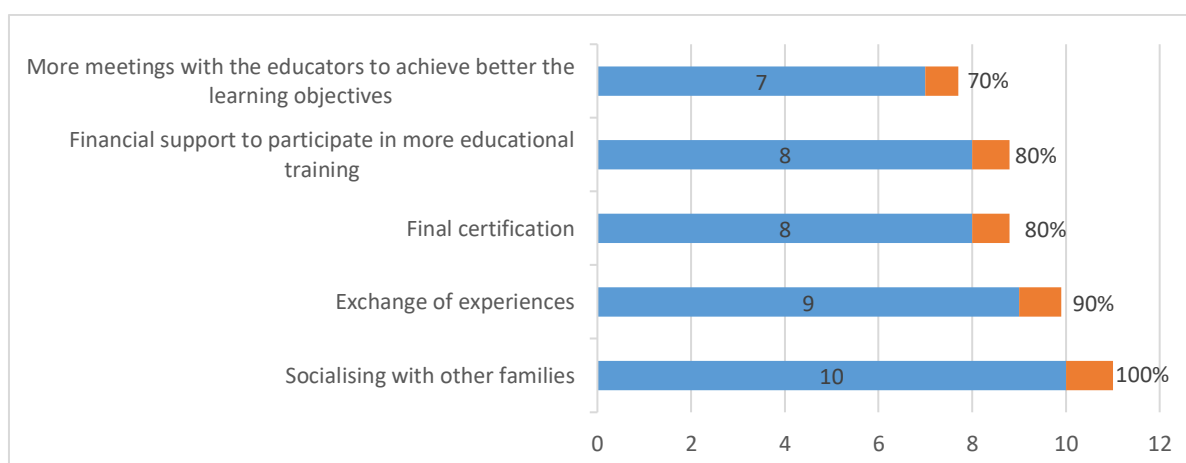


**Q7: What do AMFID need from a personal point of view during a learning activity? You can select multiple options:**



In a 1/5 scale, "confidence" obtained a high evaluation (4) and ranked first (90% of families have chosen this option), followed by "encouragement" and "empowerment" (80% - evaluation 4).

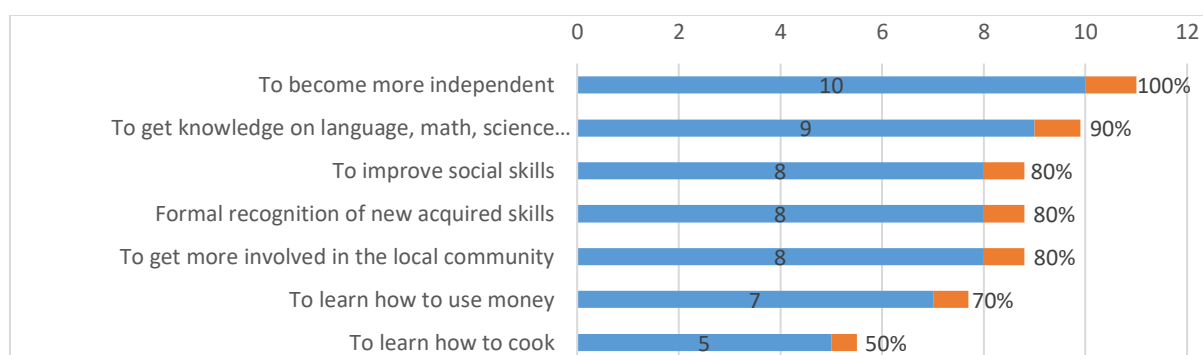
**Q8: What kind of support would improve the educational activities your family participates in? You can select multiple options:**



The majority (10 families) answered that socializing with other families would improve the educational activities they participate in. The exchange of experiences with other families would also improve these activities according to the 90% of families, followed by the opportunity to get financial support and a final certification.

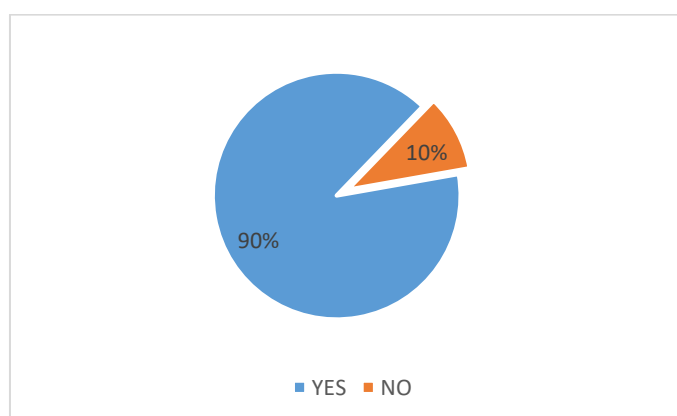
**Q9: What are the learning needs of the concerned members of your family?  
You can select multiple options:**

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100% of families answered "To become more independent" while 90% of them identified the acquisition of knowledge on language, math, science through informal activities as one of the most important learning needs of the AFMID. 8 families out of 10 selected the following learning needs: "to improve social skills, to get more involved in the local community, formal recognition of new acquired skills".

**Q10: Are you satisfied with the services you get from the institutions where your AFMID is included (school, group home, associations etc.)?**



**Q11: If no, please, explain how they could improve:**

- More social workers.

### 3.7 FAMILY QUESTIONNAIRE SUMMARY

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

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

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

### 3.8 References

[http://www.disabilitaintellettive.it/index.php?option=com\\_content&task=view&id=553&Itemid=70](http://www.disabilitaintellettive.it/index.php?option=com_content&task=view&id=553&Itemid=70)

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

<https://www.disabili.com/legge-e-fisco/speciali-legge-a-fisco/legge-104-disabili>

<http://www.filo.unioncamere.it/P42A4442C4439S0/Normativa.htm>

## 4 NATIONAL REPORT CROATIA

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

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

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

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

#### Article 62

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

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

#### Article 65

(1) Students with disabilities are:

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

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

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

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

- exercise the right to the free development of personality,
- train for employability: acquire qualifications for the first occupation, retrain, acquire and deepen professional knowledge, skills and abilities,
- Train for active citizenship.

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

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

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

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

## 4.2 DEINSTITUTIONALIZATION PROCESS OF ADULTS WITH INTELLECTUAL DISABILITIES

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

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

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

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

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

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



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

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

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

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

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

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

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

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



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

#### 4.5 QUESTIONNAIRE ANALYSIS

Different questionnaires have been deployed both to educators and families with AFMID.

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- The first questionnaire was filled out by 20 educators. 7 questionnaires were filled partially, 13 were filled completely. All 20 questionnaires are statistically relevant so we analysed them all. The analysis of every question contains the brackets in which there is a number that represents the number of educators who participated in that question. The questionnaire aimed at casting light on the motivational support methods carried out by educators in order to involve and interact with families and their adult family members with intellectual disabilities.

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

- The questionnaire conducted among households was filled out by 10 families with AFMID.

The questionnaire was divided into two parts; the first part consisted of some general information about the family; the second part consisted of 11 closed questions that were answered by the whole family.

With the questionnaire, we first wanted to find out what kind of activities do the families and AFMID attend. Second, we wanted to find out how they get in contact with educators and what are the reasons they attend some activities rather than others. Focusing on decision making process, emphasis was on finding out how the family identifies and thus decide to attend these activities together with their AFMID. We wanted to find out if the families believe they would benefit from this kind of activities (gardening and cooking) and in what way.

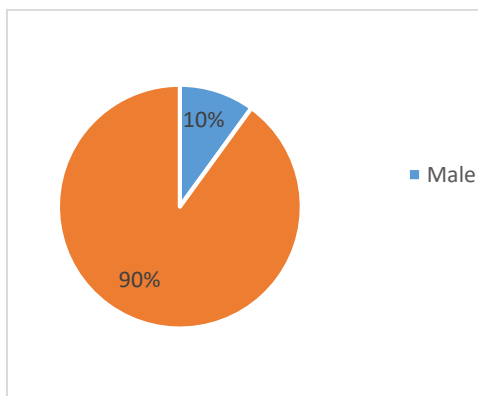
## QUESTIONNAIRE FOR EDUCATORS

### PART 1: GENERAL INFORMATION ABOUT THE EDUCATORS

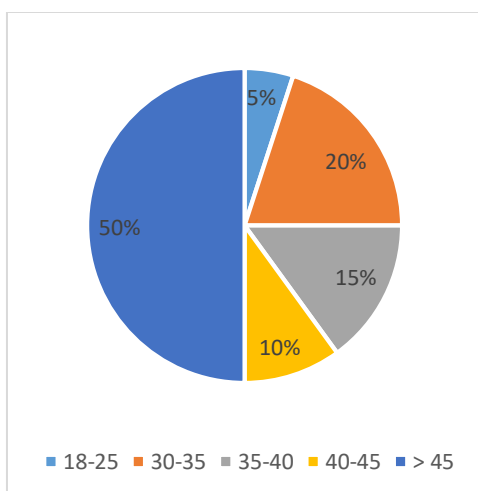
**Age and gender of educators:** 90% of educators that participated in the questionnaire (18 participants) are female and 10% (2 participants) are male. Regard the age, the most represented group is the >45 category (50%), followed by 30-35 category (20%) and 35-40 category (15%).

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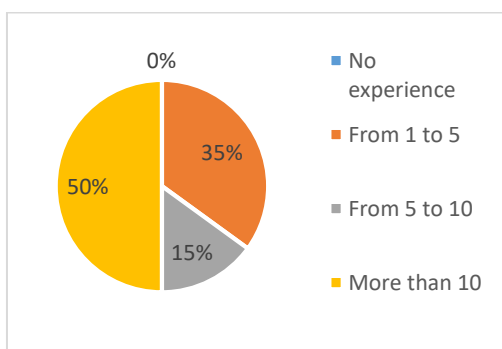
#### Are you? (n=20)



#### How old are you? (n=20)

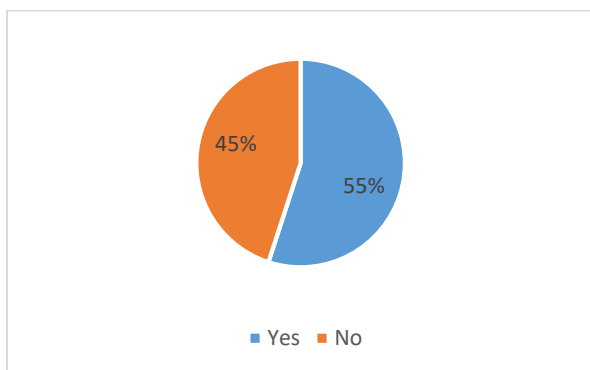


#### How many years of experience (formal and non-formal) do you have working with families with AFMID? (n=20)



## PART 2: QUESTIONS FOR EDUCATORS

### Q1: Is it easy to get in touch with families with AFMID?



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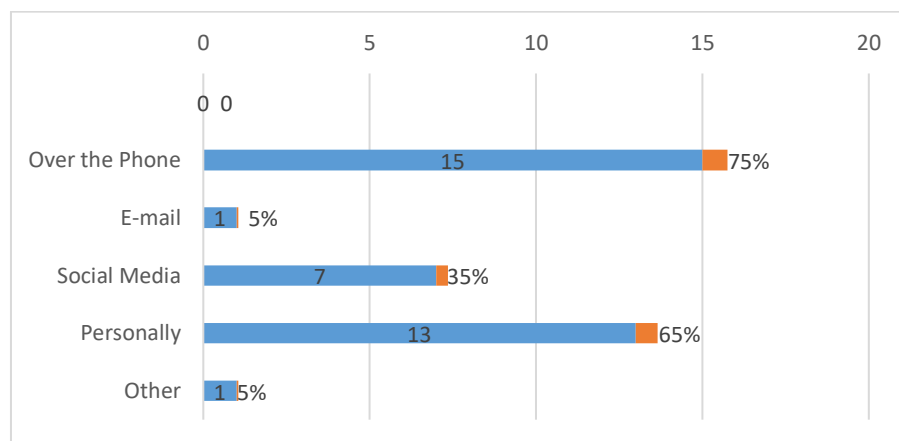
55% of the educators that participated in the questionnaire (11 participants) replied that it is easy for them to get in touch with families with AFMID, while 45% (9 participants) replied that it is not easy.

#### Q1.1: If no, what are the main obstacles in this communication? (open question) (n=9)

Answers given:

- Lack of interest (n=5)
- Closed nature of the family (n=4)
- Lack of time (n=4)
- Lack of information
- Age of family members
- Impaired health
- Poor mobility

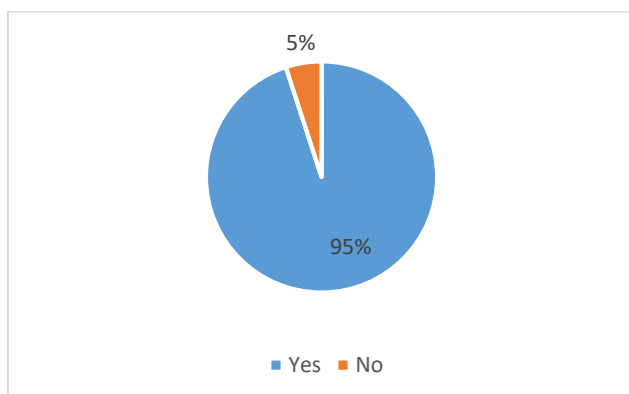
### Q2: Which are the main channels of communication do you use with families with AFMID? (n=20)



75% of educators (15 participants) prefers contact with families with AFMID by phone, and 65% (13 participants) prefers personal contact. 35% of educators (7 participants) answered that they also use social media, and 5% (1

participant) uses email. 5% (1 participant) under the option "other" answered "communication with other providers to this group of users".

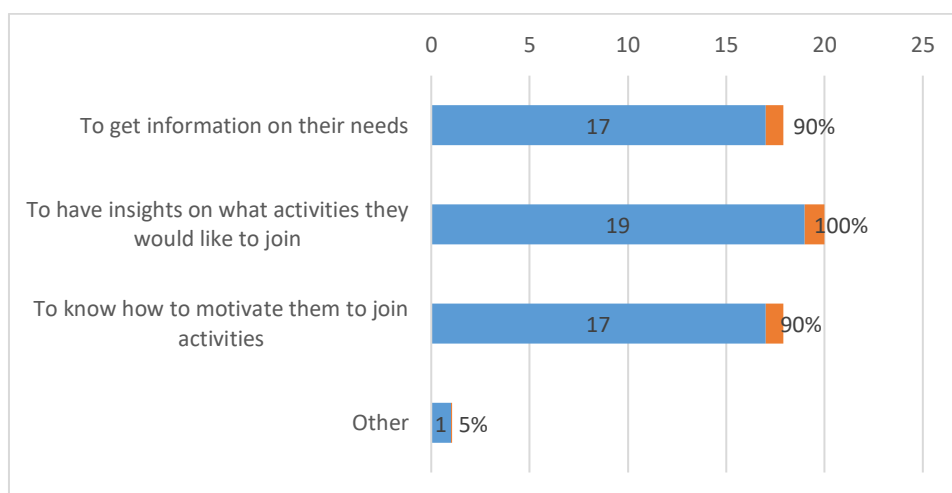
**Q3: When AFMID is included in your organization, do you perform any kind of meeting / interview / conversation with him/her family to determine their educational need/preference? (n=20)**



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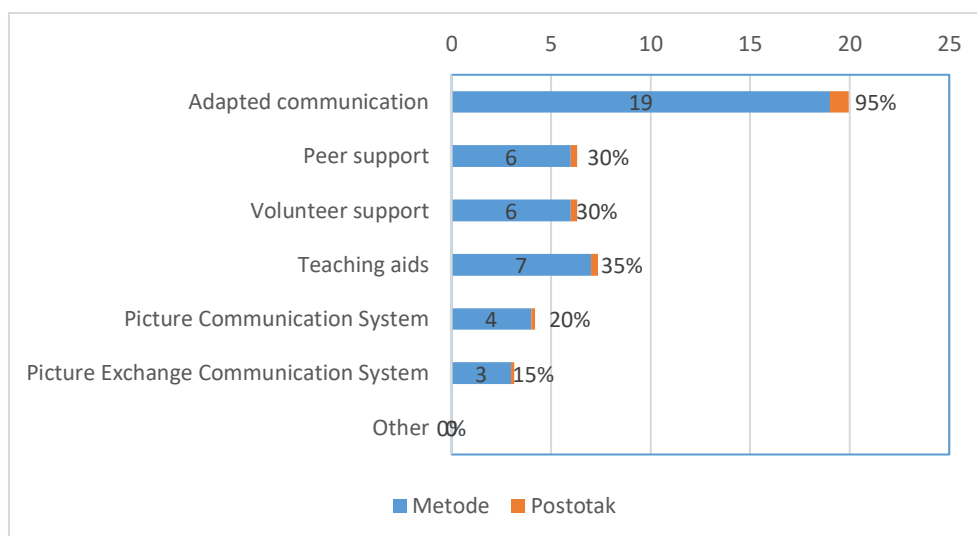
95% of the educators who participated in the questionnaire (19 participants) answered yes to this question, while 5% (1 participant) answered no.

**Q3.1: If yes, why do you think it's useful? (n=19)**



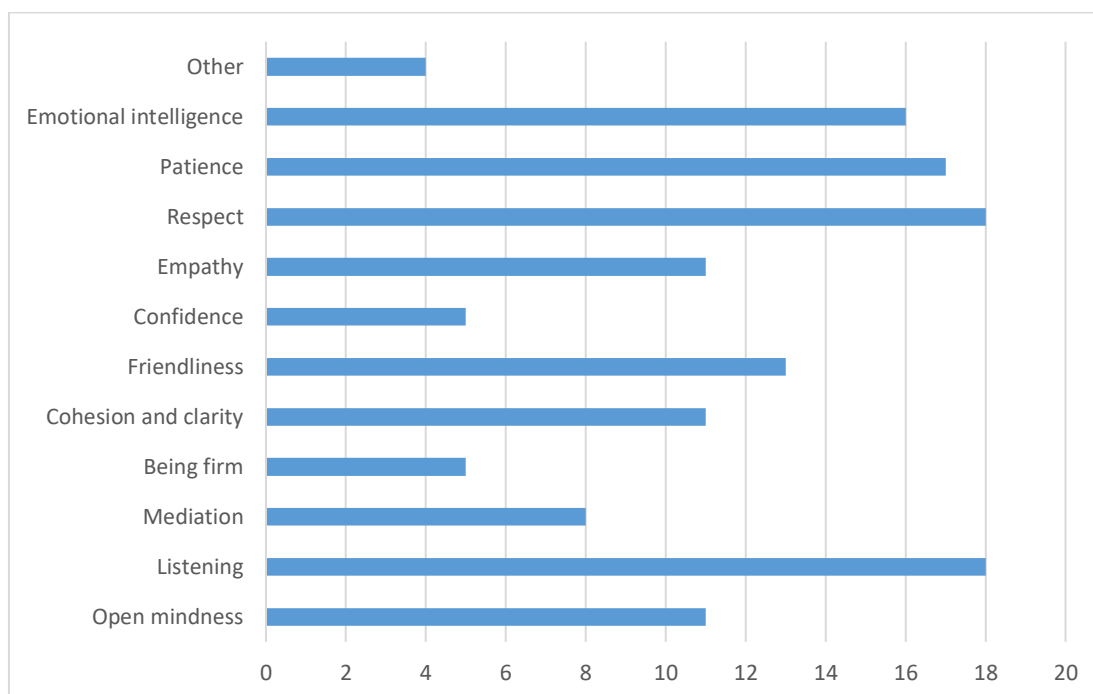
One educator under "other" responded "to evaluate existing family resources".

**Q4: What kind of methods do you use in your activities for get AFMID involved? (n=20)**



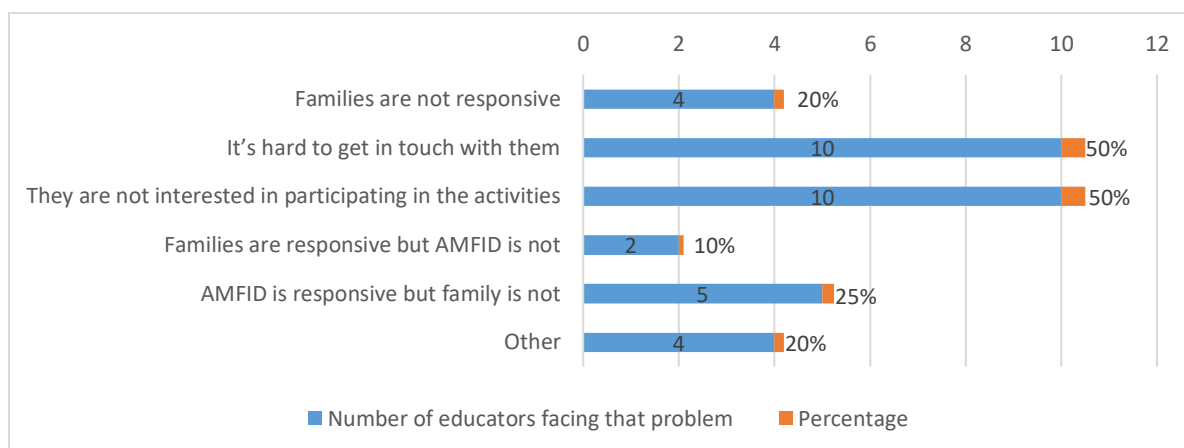
Adapted communication is by far the best method for involving families in activities, accompanied by teaching aids.

**Q5: What kind of features in the communication process with AFMID do you think an educator should have to successfully work with them? (n=20)**



The most common answers were "respect," "listening," and "patience." Under the "other" option, the answers were "social intelligence," "knowledge of the AFMID's intellectual ability", "not having too high expectations" and "responsibility".

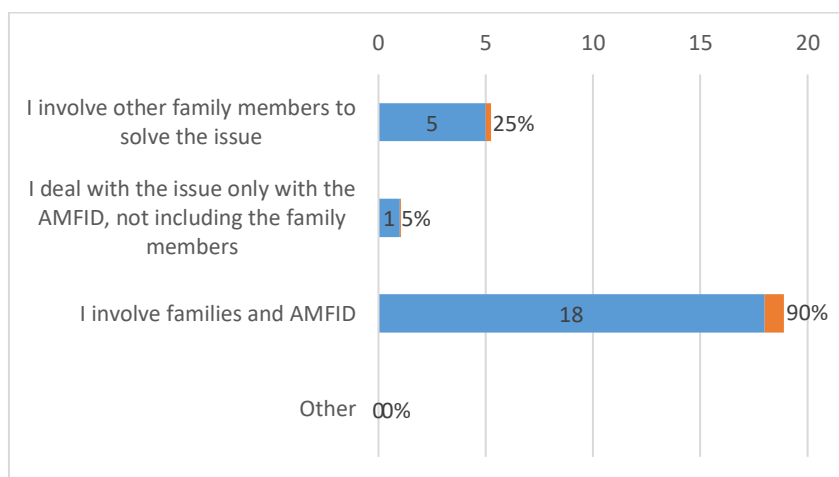
**Q6: Do you experience problems while you implement lifelong learning activities? Which problems do you meet when you work with them? (n=20)**



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50% of the educators who participated in the questionnaire (10 participants) answered that the most common problem they encountered was that it was difficult to contact the families, and that families were not interested in participating in the activities. Under the "other" option, the answers given were: "the family knows best without asking AFMID for wishes and opinions", "prejudice", "low family expectations for people with ID", "no problems, only challenges".

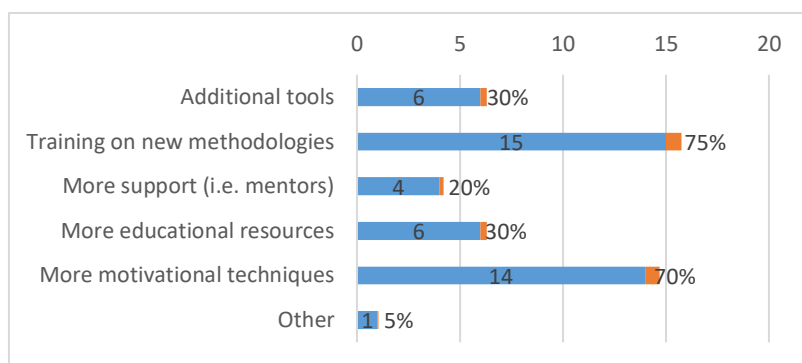
**Q7: How do you engage to resolve problems (e.g. motivational, behavioural, emotional) of the AFMID when they're engaged in lifelong learning activities? (n=20)**



90% of the educators who participated in the questionnaire (18 participants) include families and AFMID in problem solving. NOTE: 4 educators gave two answers – three of them answered "I involve family and AFMID" and "I involve other family members" and one answered "I involve family and AFMID" and "I deal with the issue only with AFMID".

**Q8: As educator, what kind of support would help you to improve during the educational activities that you deliver? (n=20)**





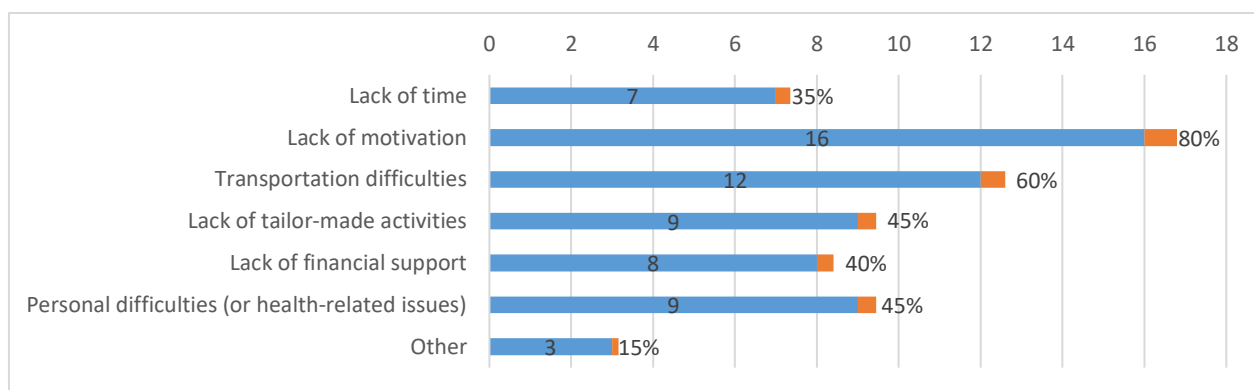
75% of the educators who participated in the questionnaire (15 participants) answered that training on new methodologies would help them, and 70% (14 participants) needed more motivational techniques. 30% (6 participants) felt that more educational resources and additional tools would help them, and 20% (4 participants) more support (i.e. mentors). Under the "other" option, one educator responded that "personally oriented planning" would help."

### Q8.1: Which motivational techniques do you find effective when working with AFMID? (n=15)

Answers given:

- Compliments (n=4)
- Associations (n=2)
- Puzzles (n=2)
- Listening to music (n=2)
- Expertise, relationships, organization (n=2)
- Good practice example (n=2)
- Prizes (n=2)
- More socializing (laughter) to be happy and looking forward to it
- Simple stories
- Encouraging social interactions
- Technique for forming relationships
- Involvement in life and work with people without intellectual disabilities
- Allowing the use of free time at the choice of AFMID
- Emphasizing the importance of participation
- Planning for the future - desired and realistic
- Personally oriented planning
- Theories of value

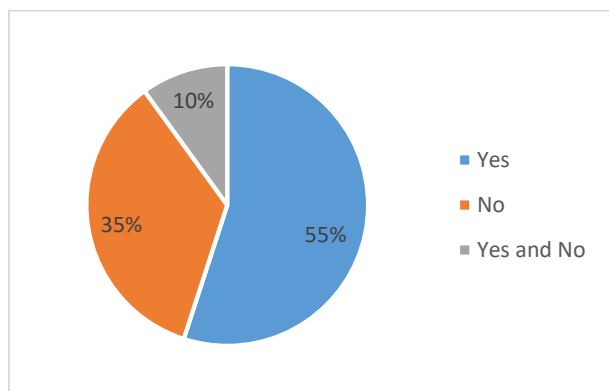
### Q9: Which are the reasons, in your opinion, that the AFMID and families are not included in activities provided for them? (n=20)



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80% of the educators who participated in the questionnaire (16 participants) believe that the most common reason why AFMID and families do not engage in activities is lack of motivation. NOTE: under the option "other" all 3 answers were given by one educator, and the answers were: - scepticism of family members, - failure to recognize the benefits of the activities offered, - inability of family members to recognize AFMID as a person worthy of dignity, a person with the right to live as others.

**Q10: Do you think that if the activities were carried out in the home environment, the AFMID and families would be keener to practice the activities? (n=20)**



55% of the educators who participated in the questionnaire (11 participants) felt that AFMID and families would be more willing to participate in the activities if they took place in a home environment, while 35% of the educators (7 participants) negatively answered this question. 10% of educators (2 participants) answered neither yes nor no.

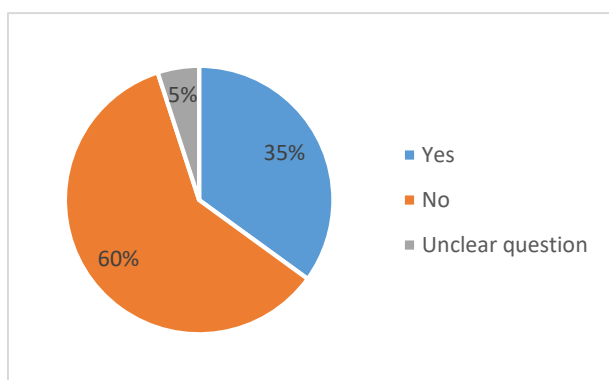
**Q11: What is in your opinion an effective communication strategy when you work with families with AFMID? (n=17)**

Answers given:

- Active listening (n=8)
- Custom communication (openness, clarity and ambiguity in communication) (n=7)
- Patience (n=2)

- Respect (n=2)
- Personally oriented planning (n=2)
- Realistic and clear goals (n=2)
- Conversation
- Willingness to compromise
- Friendly approach
- Openness
- Empathy
- Listening with understanding and adaptation
- Consistency and persistence
- Direct contact in their homes

**Q12: Do you think there is a risk of overburdening families with too much information on institutional forms of lifelong learning? (n=20)**



**Q12.1: If yes, what kind of content should be provided in communicating about LL activities to families? (n=7)**

Answers given:

- Clear and simple (n=5)
- Specific examples and evaluation results of previous projects and activities (n=2)
- Fun and custom
- More positive things
- Useful and accessible
- Encouragement
- Support
- Direct contact with the families
- Highlight the outcomes expected from these activities
- Have the family see AFMID as an adult and help find an area for education.

**Q13: Based on your experience, do you have tips for implementing LL activities for families in their own home environment? (n=13)**

Answers given:

- Motivation (n=2)
- Encouragement (n=2)
- Persistence (n=2)
- More family support (n=2)
- Better communication (n=2)
- More support from institutions (n=2)
- Active listening, respect, patience and clarity (n=2)
- Introducing innovation in the line of work
- A plan tailored to meet the individual needs of the family
- Involvement of the family and AFMID on an equal basis with the educator and opening channels for mutual transfer of knowledge between educators and family members
- Presentation of positive practices with long-term results for the independent life of persons with ID and prevention of going to an institution.

**Q14: How much is it important a positive response and motivation from the environment when involving families of vulnerable adults in lifelong learning programmes? How would you promote it? (n=15)**

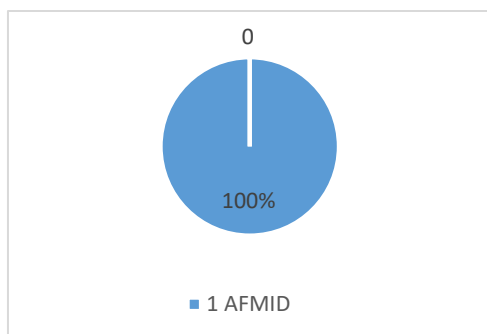
The 15 educators who answered this question thought that positive response and motivation from the environment are very important in involving families of vulnerable adults in lifelong learning programmes, and provided the following responses about promotion:

- Experience of people involved in the programs (n = 4)
- Advertising (brochures, leaflets), media (n = 3)
- Round table, presentations and stands (n = 3)
- Through social networks as a modern form of communication and websites (n= 2)
- Workshops and trainings (n = 2)
- Environmental motivation and support for families and AFMID(n = 2)
- Involvement in the local community, associations and socializing (n = 2)
- Sensitize the environment and the community (n = 2)
- Expert assistance

## QUESTIONNAIRE FOR THE FAMILIES

### PART 1: GENERAL INFORMATION ABOUT THE FAMILIES

**How many people in your family are affected by intellectual disorders?**

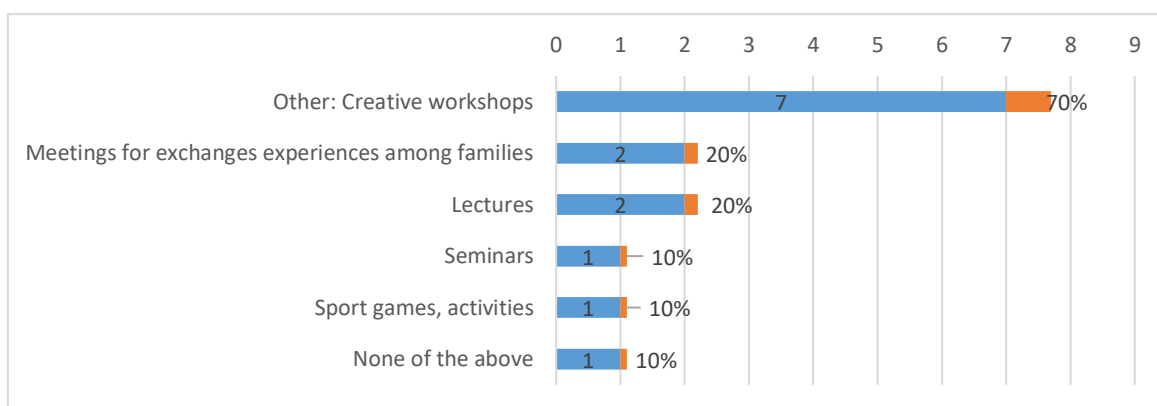


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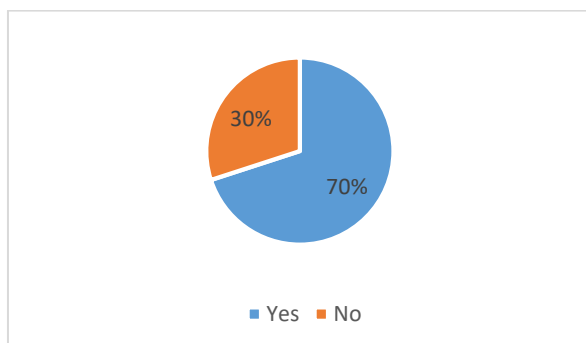
All 10 families that participated in the questionnaire (100%) have only one adult member with intellectual disabilities.

### PART 2: QUESTIONS FOR THE WHOLE FAMILY

**Q1: Which educational activities does your family participate into in order to support your AFMID?**

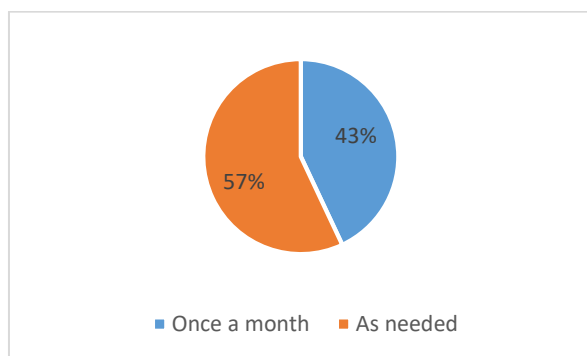


**Q2: Do you meet with educators who implement activities for AFMID before the start of them?**



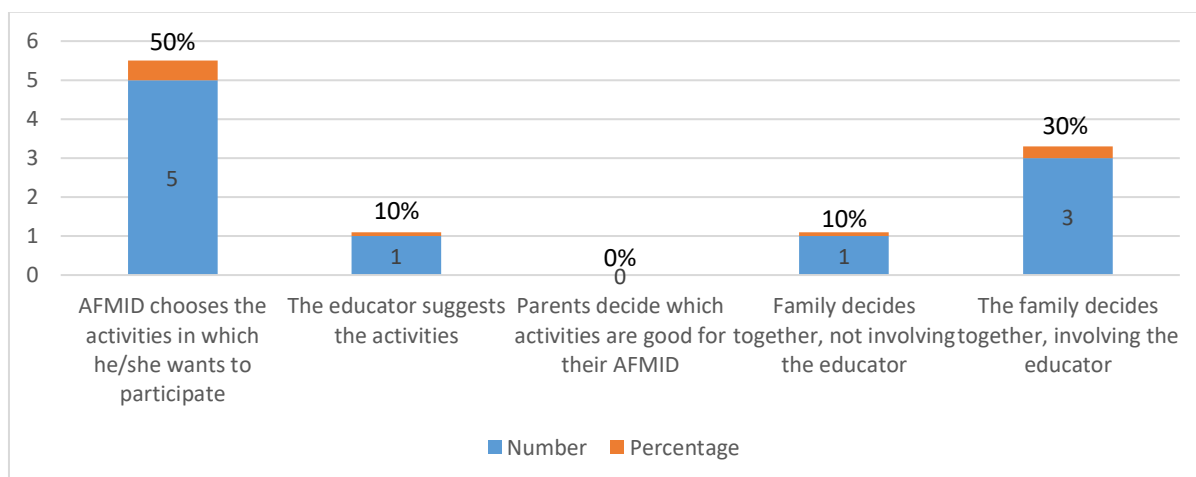
70% of the families who participated in the questionnaire (7 families) meet with the educators before conducting the activity, and 30% (3 families) doesn't.

## Q2.1: How often?



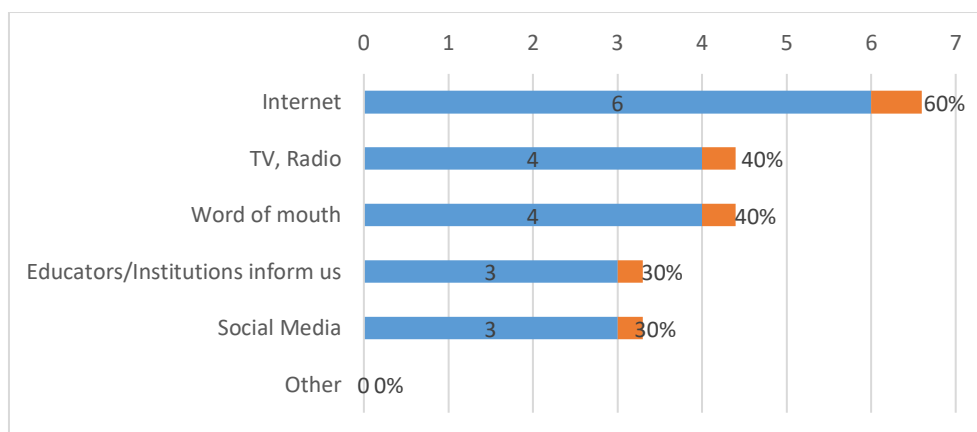
57% of families who meet with educators (4 families) do it as needed, and 43% (3 families) does it once a month.

## Q3: How these educational activities are chosen?



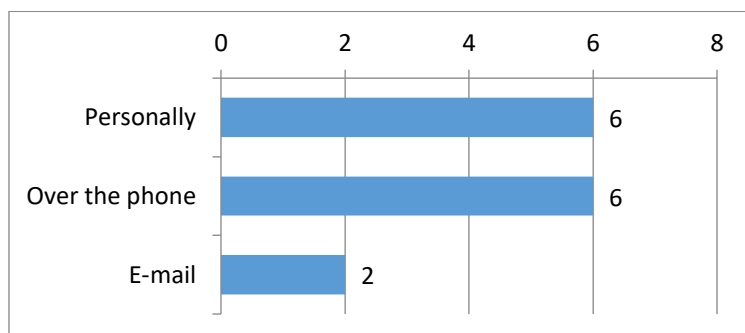
50% (5 families) answered that AFMID chooses the activities in which he/she wants to participate, and 30% (3 families) that the family decides together, involving the educator. It is significant that educational activities are not selected by parents on their own.

## Q4: How do you get informed on learning and educational activities for your family?



60% (6 families) is informed via the Internet, and 40% (4 families) via TV or Radio and by word of mouth. Only 30% of families receives information from educators / institutions and through social networks.

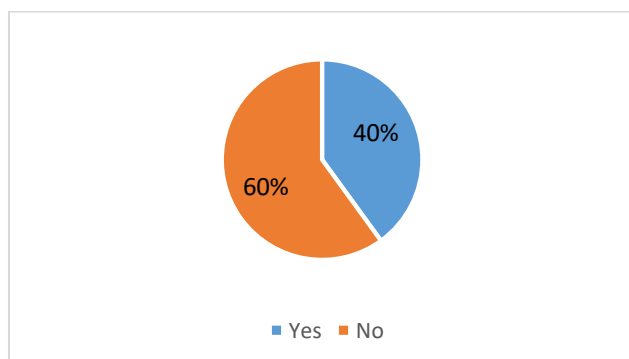
#### Q4.1: How would you prefer being contacted by institutions and educators on LL activities?



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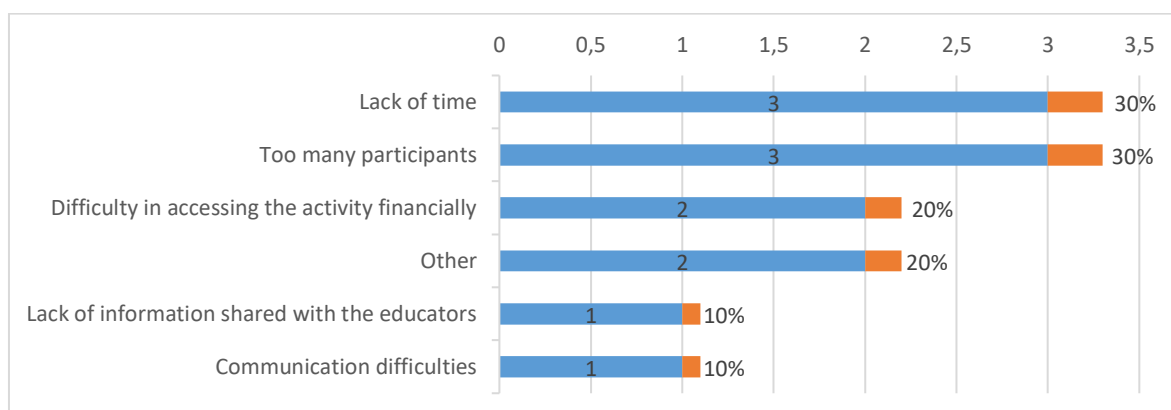
Most families prefer personal or telephone contact.

#### Q5: Do you think public services advertise their opportunities with the right communication channels?



60% (6 families) believes that public services do not advertise their opportunities through right communication channels.

#### Q6: Do you experience problems when engaged in lifelong learning activities? Can you describe the problems you meet? You can select multiple options:

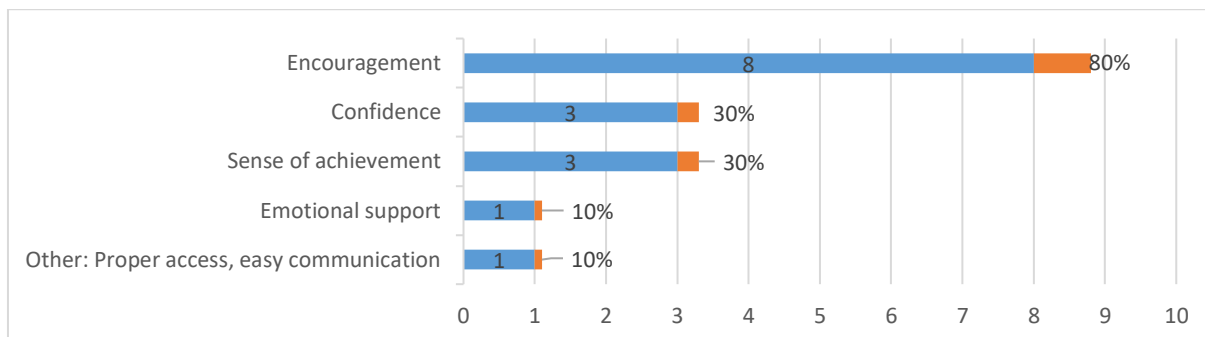




The biggest problems with family involvement in lifelong learning activities are the lack of time and too many participants, accompanied by financial difficulties. Under the "other" option, the answers are "degree of disability" and "none of the above".

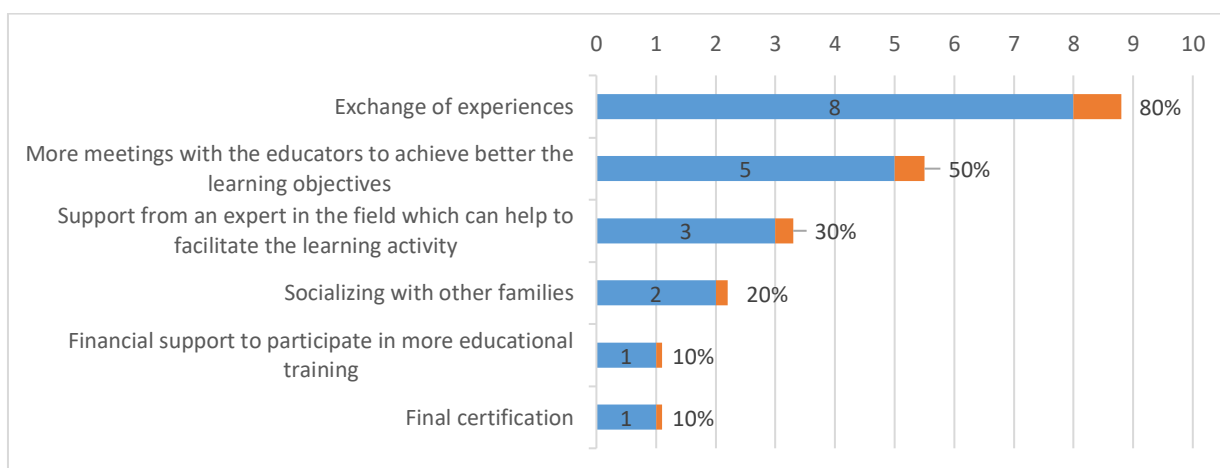
**Q7: What do AFMID need from a personal point of view during a learning activity? You can select multiple options:**

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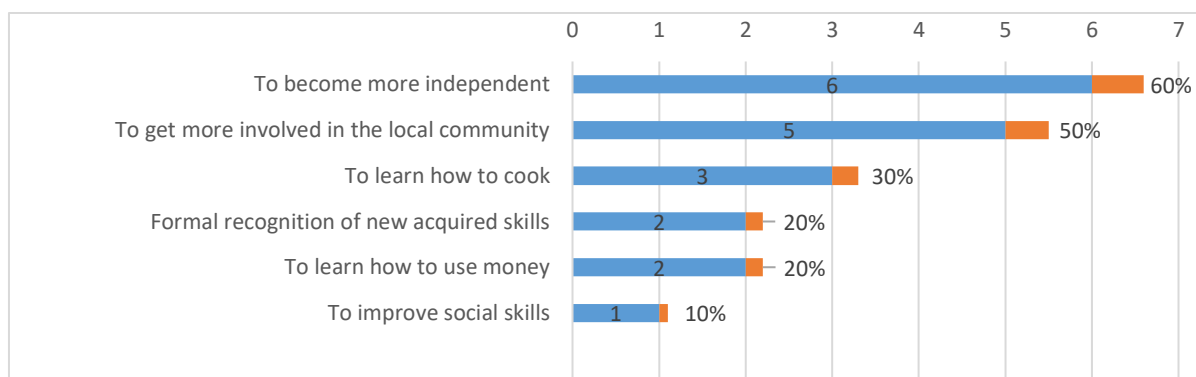
Most families (80%) think that AFMID needs encouragement the most, followed by confidence and a sense of achievement (30%).

**Q8: What kind of support would improve the educational activities your family participates in? You can select multiple options:**



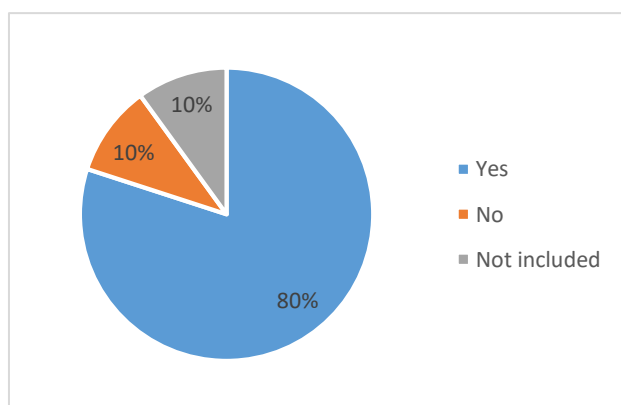
80% (8 families) responded that sharing experiences would enhance educational activities, followed by more meetings with educators, which was answered by 50% (5 families).

**Q9: What are the learning needs of the concerned members of your family? You can select multiple options:**



60% (6 families) answered "to become more independent", followed by "to get more involved in the local community", which was answered by 50% (5 families).

**Q10: Are you satisfied with the services you get from the institutions where your AFMID is included (school, group home, associations etc.)?**



**Q11: If no, please, explain how they could improve:**

Answers given:

- So that maintained activities do not fall into routine, but are upgraded with new content
- More information on activities and services

## 4.6 QUESTIONNAIRE SUMMARY

### Educators

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

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

### Families

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

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

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## 5 NATIONAL REPORT UNITED KINGDOM

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

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

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

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

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

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

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

### 5.2 SCHOOLING FOR INCLUSION

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

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

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

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

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

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

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### 5.3 LIFELONG LEARNING FOR PEOPLE WITH LEARNING DISABILITIES

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

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

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

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

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

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



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

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



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

## LITERATURE

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## 5.5 QUESTIONNAIRES ANALYSIS

Two questionnaires were created for IO3, one for educators and one for adults with LD and their families. In the UK, all the questionnaires developed for this initial phase of MeTura were combined in to two larger questionnaires (one for educators and one for AFMID and their families) since it was decided that this was an easier way to engage respondent and required less time commitment. The educator questionnaire was completed by 20 respondents. These included educators working in formal education (colleges etc.) and those working with community and charity organisations providing LL and occupational activity for adults with LD. The adult with LD/family questionnaire was completed by 23 respondents. The combined data was then separated out to extract the data for the specific IO3 questions.

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The questions for educators aimed to identify the motivation support methods used by educators in order to engage and interact with adults with learning disabilities and their families. This questionnaire was divided into two sections: the first section consisted of questioned to gather some general demographic information about the educator; the second section involved 12 closed and 6 open questions about the communication process between educators and families or educators and adults with learning disabilities. In particular, the questionnaire sort to identify the strategies used by educators to get the AFMID involved as well as motivational techniques used when working with the AFMID. We also gave the educators the opportunity to express their own opinion and share their experiences about LL activities with families with AFMID.

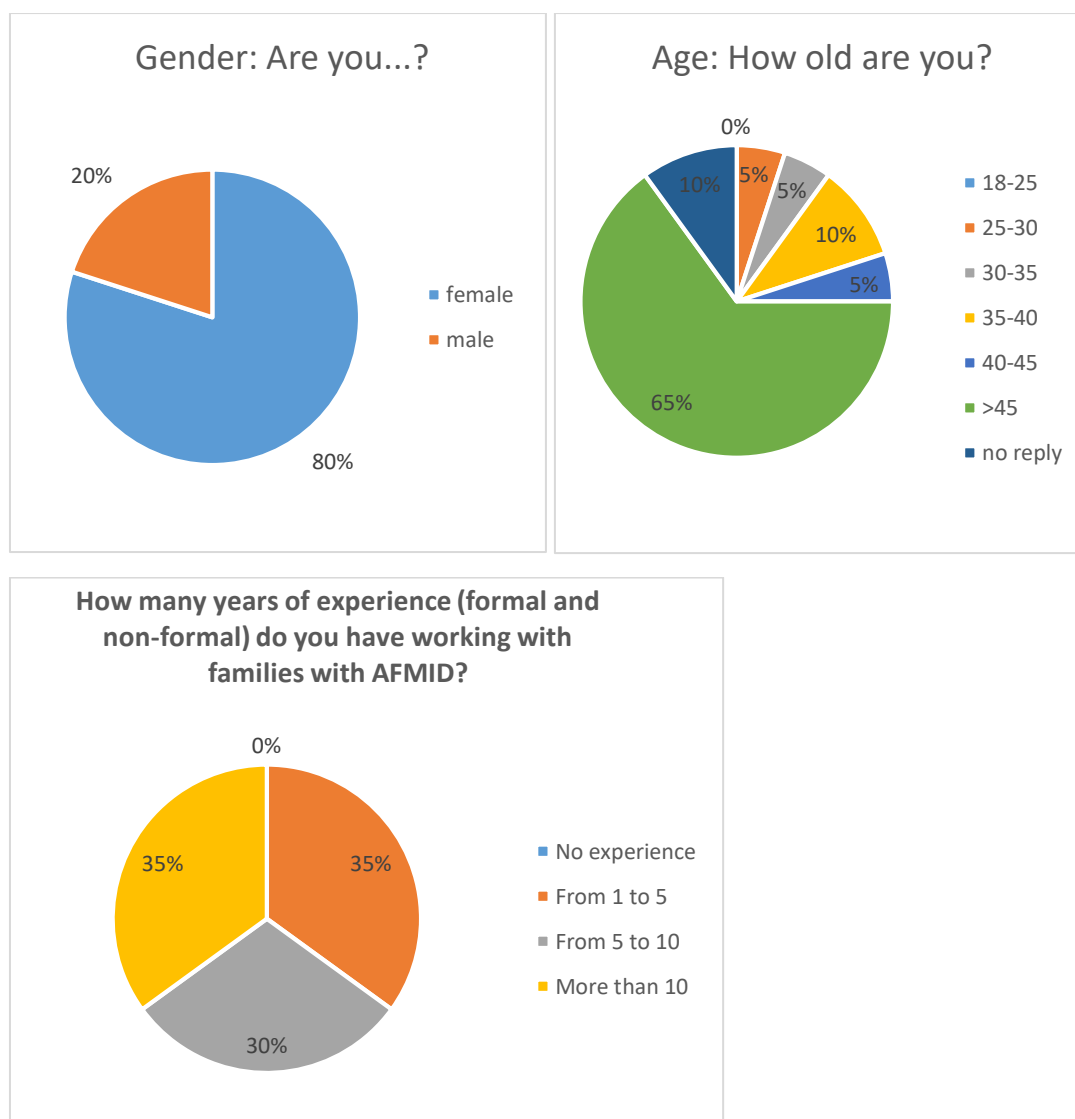
The questionnaire for adults with learning disabilities and their families was also divided into two parts. The first consisted of general questions about the family; the second consisted of 11 closed questions to be answered by the whole family. This questionnaire aimed firstly to identify the kind of activities that adults with LD and their families attend and secondly to find out how they get in contact with educators and how they select the activities that they attend, in particular focusing on how they identify and make decisions about which activities to attend. We wanted to find out if the families believe they would benefit from gardening and cooking activities and if so, what they believed the benefits might be.

## QUESTIONNAIRE FOR EDUCATORS

### PART 1: GENERAL INFORMATION ABOUT THE EDUCATORS

**Age, gender and experience of educators:** The significant majority of educators were female (80%) and aged over 45. (65%) This may be because working with adults with LD in non-formal settings (particularly in the charity and community settings) is often a second career for many educators. These roles are also generally low paid or self-employed. All educators had some experience of working with families with AFMID with roughly equal percentages for 1-5 years, 5-10 years and more than 10 yrs.

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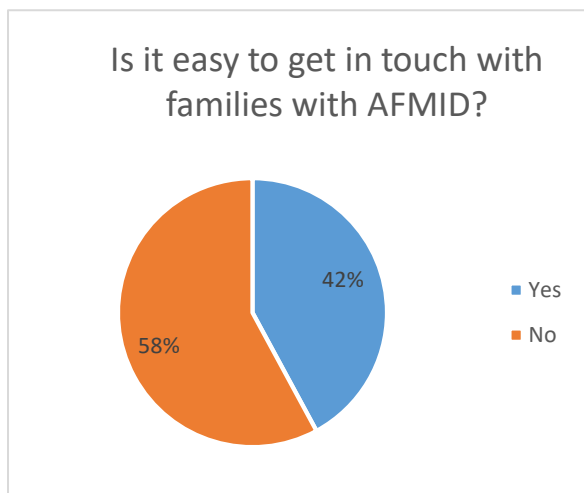


## PART 2: QUESTIONS FOR EDUCATORS

### Q1: Is it easy to get in touch with families with AMFID?

#### Q1.1: If no, what are the main obstacles in this communication? (open question)

58% of educators said that it is not easy to get in touch with families with ADFMID



The main obstacles that they described where:

- No family or family not in the local areas. Adults with LD living in supported living or independently because immediate family is no longer alive and extended family are at a distance or family or adult have moved away. Carers in these environments often change frequently.
- Independence from family is often a goal for the adult with LD. In some cases, they have contact details for families but their aim is to promote independence for AFMID, so family are not consulted.
- Distrust & bureaucracy. communication routes through government organisations (who may be the funders) can be long, slow and complicated. This is especially true where statutory authorities have had to be involved which are often distrusted by families
- Some families have difficulties accessing social media (especially where the parents have LD)
- Families often work and are not available to contact by educators in normal working hours.

If no, what are the main obstacles to this communication? Open-Ended Responses.

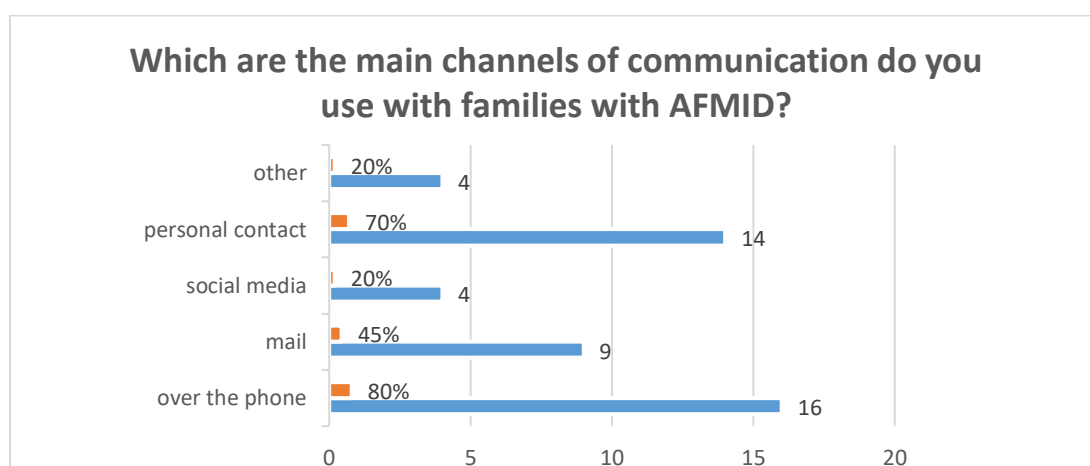
- Sometimes if they are older adults, their parents may have passed away & have lost contact with other family. Carers often seem to change on a regular basis, so continuity is extremely hard.
- I work with young people with ASD specifically and we often find families are trying to cope with little or no help from Social Care or they don't have an EHCP (if under 25). Trying to communicate with these local government departments to offer our service to families with young adults with ASD. Funding is usually the main obstacle. We are now trying to communicate through GP services to see if we can reach more service users in this way.
- Adults may be living in assisted living, ward, controlled housing with independence from family as a lead objective There may be a

significant chain of communication between all engaged stakeholders  
Initial contact may only occur at one-time event

- Many people we support live in supported living and family may not live close by. Some families work so we aren't able to phone them or able to meet up regularly for reviews unless it is out of day centre hours. We will conduct meetings in family homes if this is the case, in the evening. IT - some families have difficulty accessing emails and many don't use social media. Some families may have learning disabilities themselves.
- Contact details sparse
- Sometimes they are at work?
- Adults with LD often living in supported living environments rather than with their own families, so less contact with families
- Many of our learners are living in care homes, so we don't regularly have direct contact with the families. We don't have a clear procedure on how to engage and communicate with families- so certainly much of this current barrier is with us.
- Distrust in the service, Age is also a factor and distrust of people they feel are in positions of power
- If needed, we have ways of communication and engaging with families
- Quite often referrals come through from statutory services who have got involved with families because things have got serious, perhaps with money, the care of children or mental health, to name a few. Unfortunately, when we step in to support them it is evident that they are often isolated and do not have an understanding of services available to them. Fear or authority is something we often deal with and can be a barrier to getting support.

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## Q2: Which are the main channels of communication do you use with families with AFMID?



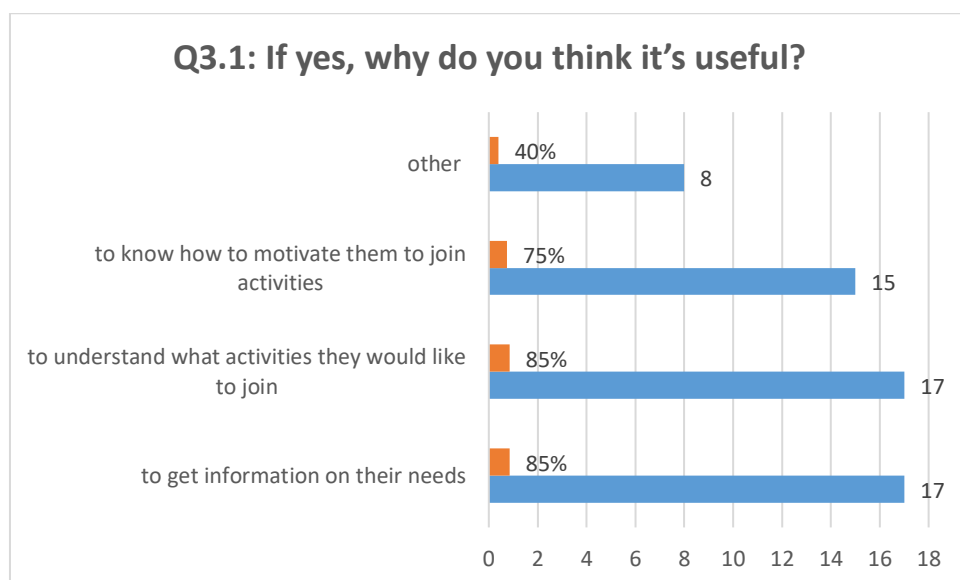
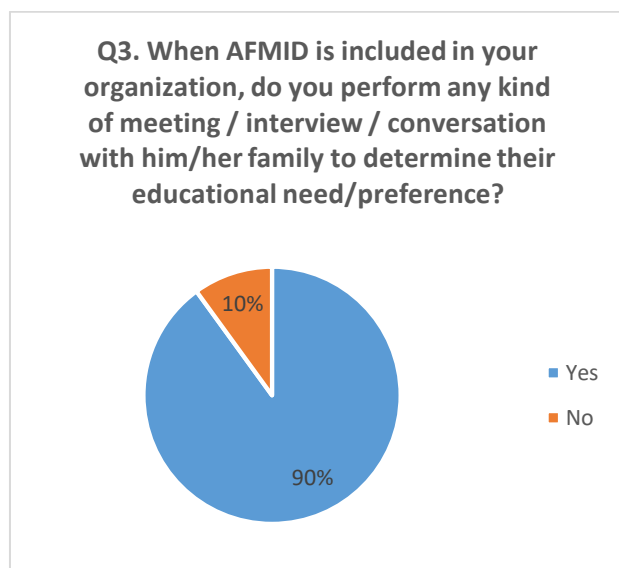
The main channels of communication with families with AFMID are over the phone and in person. Only a small percentage use social media

Other responses

- Database Coffee mornings at our premises
- WhatsApp group
- Umbrella organisation called SOCIAL FARMING IRELAND
- We have simple communication books, which travel between us and home with the individual on a daily basis.

**Q3: When AFMID is included in your organization, do you perform any kind of meeting / interview / conversation with him/her family to determine their educational need/preference?**

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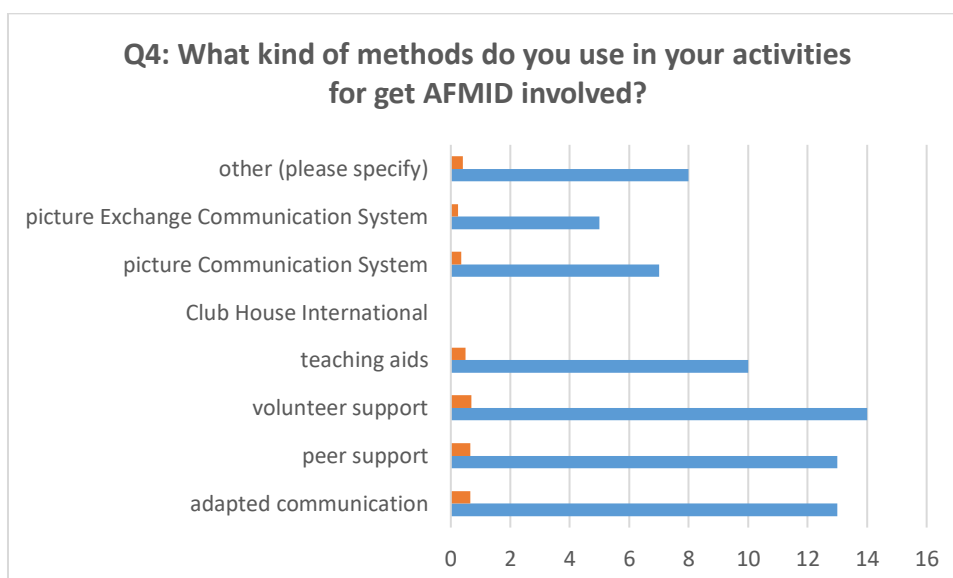
Other responses

- When planning activities, it's really helpful to know if there are any barriers to an individual participating so that adjustments can be made that are likely to increase the possibility of the individual participating & gaining a valuable experience/ skill from taking part.

- Part of nhs person centred care approach May need to establish support or supervision
- It's helpful to have some background on the new client, overtime we'll get to know them first-hand and this might change our approach
- We meet, have a look around the farm and become familiar with one another. It works both ways.
- to meet the needs, wishes and preferences of the individuals we work with
- We would encourage either family or support worker to be at initial meeting so we could best explore what avenues would work best for the individual we are working with.
- it is also useful in goal setting
- This is generally done with the individual, rather than the family although this may be the case if the individual lacks capacity.

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#### Q4: What kind of methods do you use in your activities for get AFMID involved?



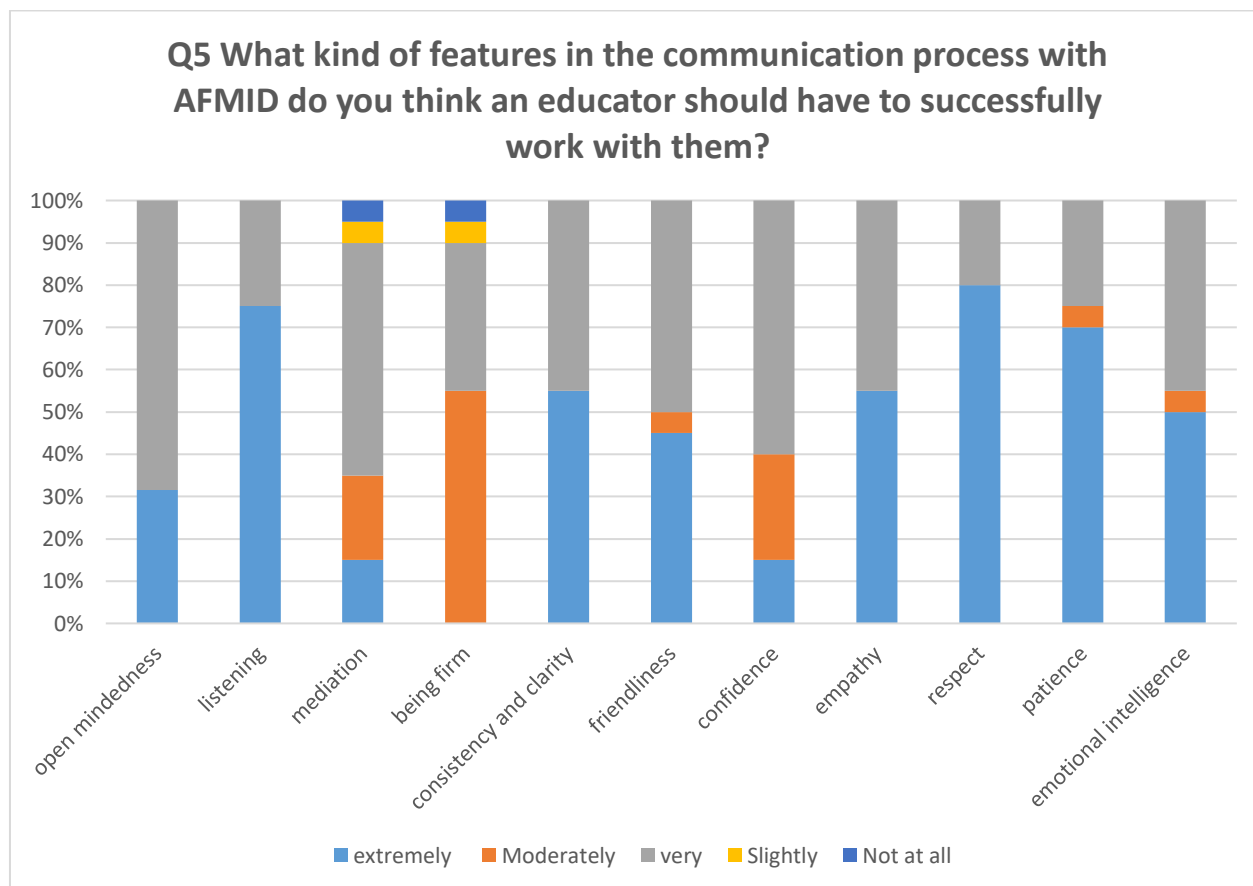
Adapted communication and support from peers and volunteers were the main methods for getting AFMID involved.

#### Other responses

- Promise of a medal or certificate of achievement or sticker, particularly for physical activities.
- ASDAN employability skills training.
- Choice of activities
- Humour
- actually showing them the garden and explaining the activity
- We are always looking at ways to support, improve and develop communication for everyone attending our service.
- Makaton signing
- Adapted tools



**Q5: What kind of features in the communication process with AFMID do you think an educator should have to successfully work with them? (multiple choices possible) – scaled questions (1/5)**



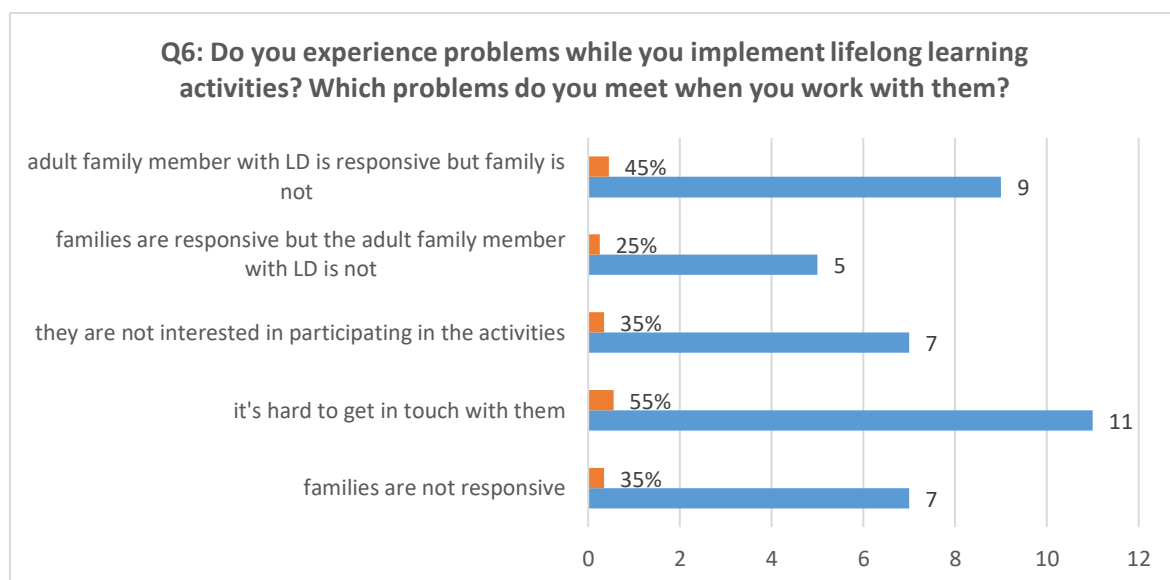
81

Most common answers are listening, respect and patience although consistency, empathy and emotional intelligence were also considered important

Other responses

- Focusing on ability rather than disability is a really important mindset to have.
- It is important to treat each adult as an individual and home in on their likes and dislikes.
- All important, have just tried to pick out which work best for me

**Q6: Do you experience problems while you implement lifelong learning activities? Which problems do you meet when you work with them?**



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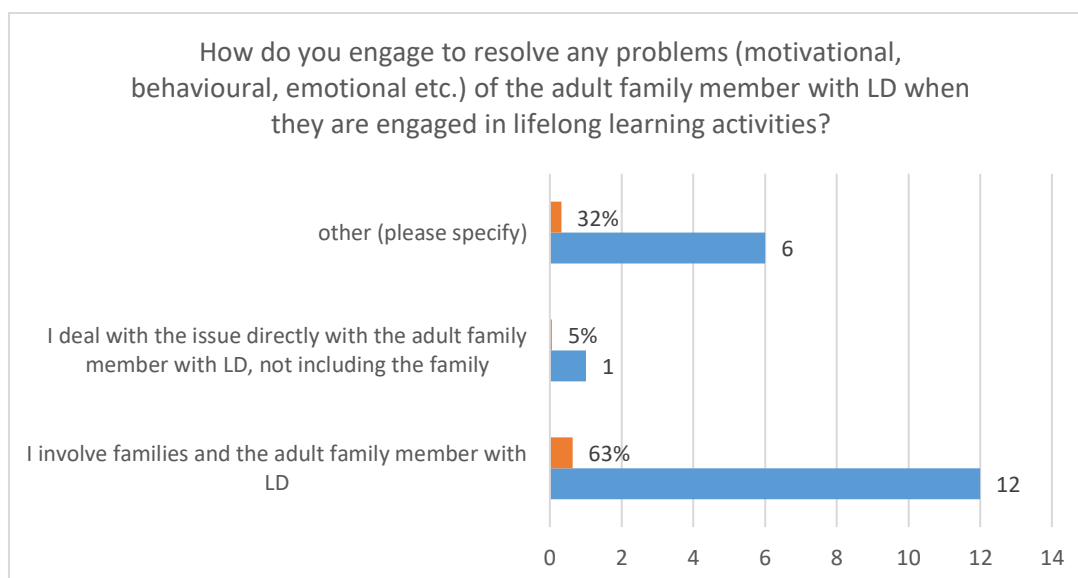
Main issues are the difficulty of getting in touch with the families or of them not responding to approaches.

Other (please specify)

- Families often do not have the time to engage in activity at time I'm available due to their working commitments/ other caring duties.
- Sometimes family members are desperate to seek help/activities for young adults with LD but adult with LD is not always interested/co-operative. They have to be engaged for us to help them.
- May not see relevance to the adult or themselves
- The service providers have become tired and weary. It's a challenge when you have different abilities in one group
- Some clients show little interest in project
- We aren't currently working with the goal to educate families as well as the individuals we support.

**Q7. How do you engage to resolve any problems (motivational, behavioural, emotional etc.) of the adult family member with LD when they are engaged in lifelong learning activities?**

Majority of educators involve the family in discussions about issues but several stated that they would only do this with the consent of the AFMID. Where adults were referred by care organisations, then these would also be involved in the discussions

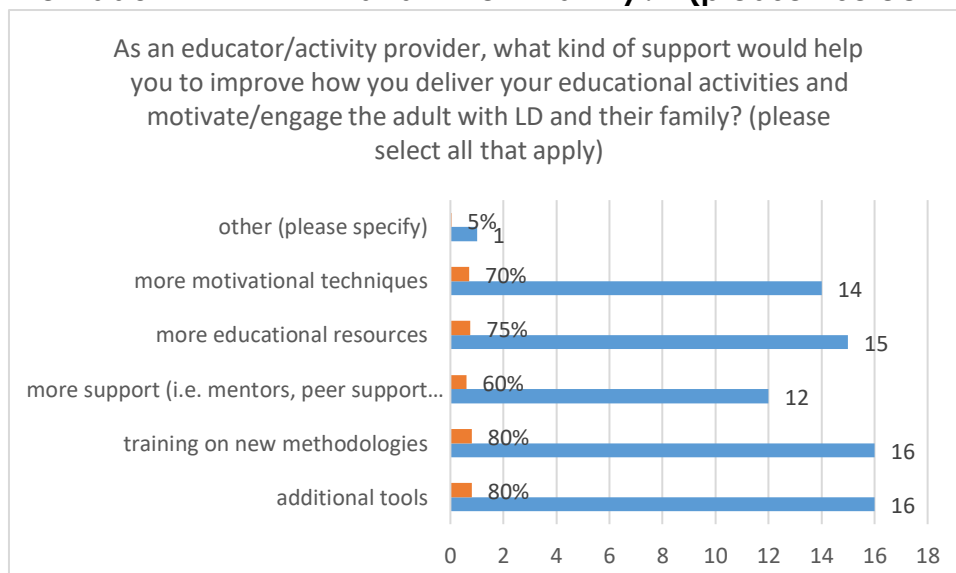


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#### Other options/comments

- Need the adult with ID consent to contact family
- Negotiate with the Social Farming Co-ordinator for my area.
- We would take the approach to work with individual and seek their permission to speak to family or wider circle of support only if necessary
- also involve carer/organization's behavioural specialist
- or through the care management/appropriate contact person
- Generally, day to day issues can be resolved working directly with the individual. If they choose to share information with their families, this is their choice. If the matter was of greater concern, then we would seek professional advice from any relevant agency to assist in resolving the matter.

#### Q8 As an educator/activity provider, what kind of support would help you to improve how you deliver your educational activities and motivate/engage the adult with LD and their family? (please select all that apply)



Training and tools were the most popular kinds of support that educators would like although techniques and resources were also key. One respondent commented that “ More time to source these things” would also be useful

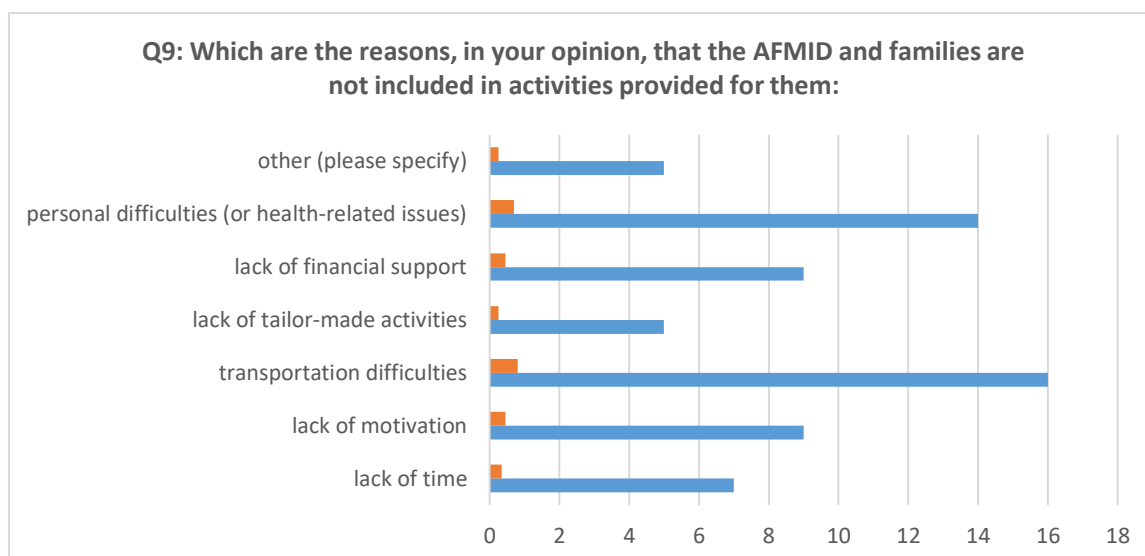
### **Q8bis: Which motivational techniques do you find effective when working with AFMID?**

- Positive encouragement Lots of praise Suggesting they try something for a few minutes & then stop if they don't like it, as at least then they've tried it. Rewarding with a certificate, sticker, sweet.
- Find what activities they are interested in learning, what skills they have to engage their interest. Promote self-esteem and confidence by breaking down tasks into manageable steps and giving full explanations.
- Choice of activities, break task in to chunks, differentiation, graded press, humour, reward e.g. praise, use of music choice in background, indoor outdoor choice, position of the expert A final product
- Praise and encouragement Taking produce/products home that the individual has made. Keeping a photo journal
- Having fun, having interesting activities, explaining the reason for doing things in a certain way, giving ownership over to the adults so they develop the ability to make their own judgements.
- Trust, clear explanations, end product, positive responses, outdoor activities
- Encouragement laughter working at a pace that is appropriate for the individual sharing learning making mistakes and learning from them no judgement
- Good humour, jokes, music
- Encouragement. Making the individual feel they are achieving in their role.
- liveliness is important as is explaining the task and the outcome
- Developing and building good positive relationships. Positive reinforcement of the individual's work/activity Celebrating success/rewards Peer support/groups Meetings/reviews/setting goals The environment we work within helps motivate us
- Making things fun. Monitoring so that progress can be seen, Rewarding progress made.
- I find that peer support is often the best way to empower someone. The people we work with often feel isolated and lonely and to know they are not alone has a profound impact on an individual.

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### **Q9: Which are the reasons, in your opinion, that the AFMID and families are not included in activities provided for them:**

The main issues that prevented AFMID and their families joining activities related to transport and to personal/health related issues.

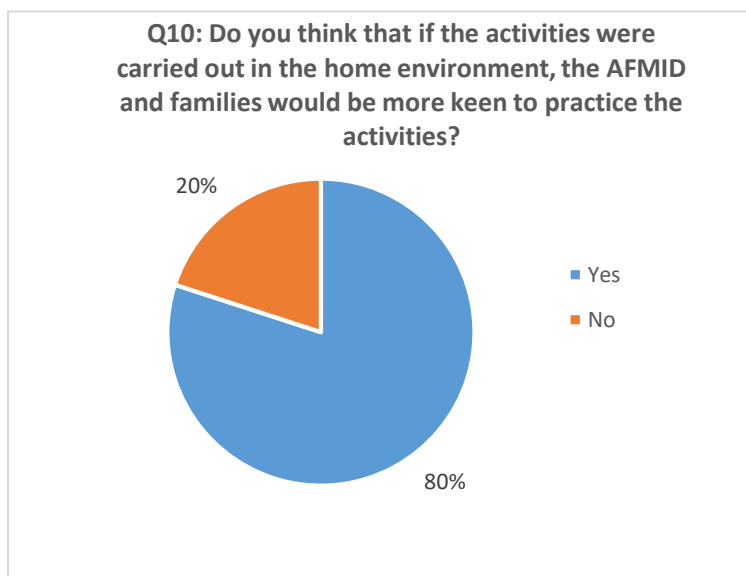


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#### Other comments

- In our service provision the adults with ID come to 'work', so there is a separation between home and work
- Families often work or may have health issues themselves.
- lack of one-to-one support
- Ageing parents
- Sorry difficult to comment in a general fashion on this one.

#### Q10: Do you think that if the activities were carried out in the home environment, the AFMID and families would be more keen to practice the activities?



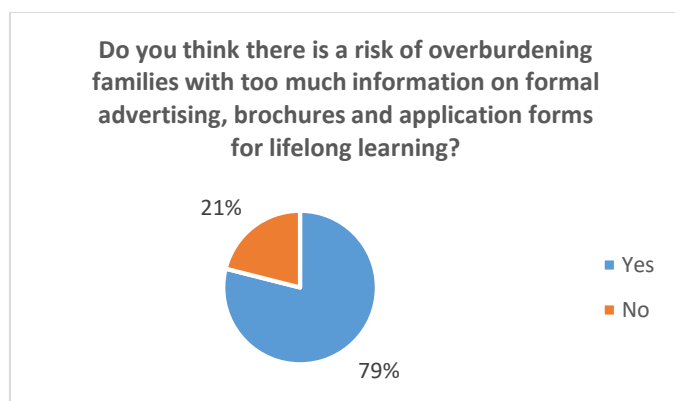
#### Comments

- not sure, there is much benefit from a mixture of both learning at home and being in the community
- Again I'm not sure, I think it would depend on the individual and their family and how they viewed the activity.

#### Q11: What is in your opinion an effective communication strategy when you work with families with AFMID?

- Easy read information, colourful, lots of pictures, informal language where possible.
- Encouraging families to participate in the activities alongside the adult with LD.
- keeping an open mind and being flexible
- A clear achievable goal, in a set timeframe agreed at the beginning of the project
- Having an accessible format with a clear objective to worth the towards an outcome.
- Not applicable to me/
- Keeping things simple and accessible. Use of social media to allow families see the enjoyment that their family member gets from the activities.
- Open days and workshops. Tours and visits examples of positive change and benefits
- Lots of communication
- Remaining positive but also making sure they feel listened too. Giving time when needed to step away and not forcing them into tasks
- Being involved from the start- as a specifically designed part of the whole learning process, i.e. a very clear expectation as to what the involvement of the families will be- ahead of signing up for a course. Possible online- in a similar way to how school do this- e.g. through Tapestry.
- Not sure
- Getting families to recognize possible benefits may have to health and wellbeing.
- I think offering tailored support is key. We do home visits initially to get a good understanding of the family's needs. This then helps to build trust in us which can then encourage them to get involved with the service we are offering. We will speak to people on the phone, via text or social media depending on how they best communicate. Breaking down barriers is key.

**Q12 Do you think there is a risk of overburdening families with too much information on formal advertising, brochures and application forms for lifelong learning?**



### If no, how can we ensure this is prevented?

- Monthly newsletter
- They currently receive little from us so plenty of scope to increase this. Ask them how they would like to be communicated with. Check in with them on this.

### Q12.bis If yes, what kind of content should be provided when communicating about lifelong learning activities to families?

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- Basic Information on types of activities that can aid lifelong learning at home with links to useful resources adult can access in their own time if they choose to. Links to local organisations to the specific person being addressed about learning opportunities rather than national ones.
- By inviting them to informal meetings with other families. Show round facilities.
- Outcomes, commitment of time and or money, travel. How to access further information and who to contact
- Families are often already juggling a lot and have time restraints or financial restraints. They may just feel they haven't got the energy. Letting day services take the majority of the responsibility and only giving families one thing at a time to work towards with their family
- The importance of purposeful activities for wellbeing.
- what, where, when try before you buy - taster sessions cost, where to seek funding
- Basic guides
- benefits to the whole family
- Update on projects Specifics on their learning/ progress National studies and events
- Keep it simple, highlight likely benefits, make it feel achievable so that even small changes might reap significant benefits.
- The families we work with are often overloaded with paperwork from statutory services and will quite often struggle with reading it. We offer mentoring support to help with this. A mentor can help sift through paperwork and help the person to understand it.

### Q13 Based on your experience, do you have any tips for implementing lifelong activities for families that they can continue to do at home?

- Make sure activities are fun, easy, affordable & focus on what the individual can do rather than what they can't do. If someone doesn't want to do it on one day don't give up they may just be having a bad day & feel like engaging another time.
- Inviting families to learn alongside adult with LD. Maybe encourage them to participate as volunteers with the organisation.



- giving them task, which they can complete at home and then share with pictures on what WhatsApp
- All agreeing at annual reviews a plan for the upcoming year and working towards objectives together.
- Keeping activities real - repeating activities so that learners can be confident in their own abilities.
- Keep activities simple, clear. Draw step by step guides Punctuation and regular attendance
- Make sure results are forthcoming. An example would be if growing vegetables make sure they get to try the fruits of their labour and appreciate what their hard work has resulted in.
- Taking things home that they have done during an activity session.
- Changing habits is key and offering long term support. Short term intervention does not work and people are distrusting of people offering it, in my experience. Getting people outside working on an allotment, feeling part of a community has made huge changes to so many of the people I work with. They are then better equipped physically, mentally and emotionally to go away and make real changes in their lives at home for both themselves and their families.

**Q14 How important is it that the environment in which the lifelong learning takes place encourages and motivates adults with LD and their families to engage with the learning? What other ways could be used to promote a positive, motivating impact from the environment in which lifelong learning takes place?**

- Providing individuals with somewhere to display their work where others can see it e.g. on a display board. Allows for opportunity of praise from others, social interaction and sense of achievement. It can also be motivating for others to engage in activity as they may achieve something similar.
- I definitely think it is important to engage adults with LD predominantly in a less formal environment and provide them with practical hands on skills rather than too much classroom work.
- peer support and a place where people find likeminded people
- Our place is open to public, we have themed events and open days, the process of the day stays the same, We also have a Christmas meal together in the local hotel, our carol concert in the community church. Daily, our adults with ID are out in their community- supported and supervised- making deliveries, work experience
- Very important. Access to other community projects and wider experiences is important too.
- Very important
- It is very important and must be on a real life situation. Practical activities rather than theory.
- Very important for the learning environment to be welcoming, positive and relevant to the activity.

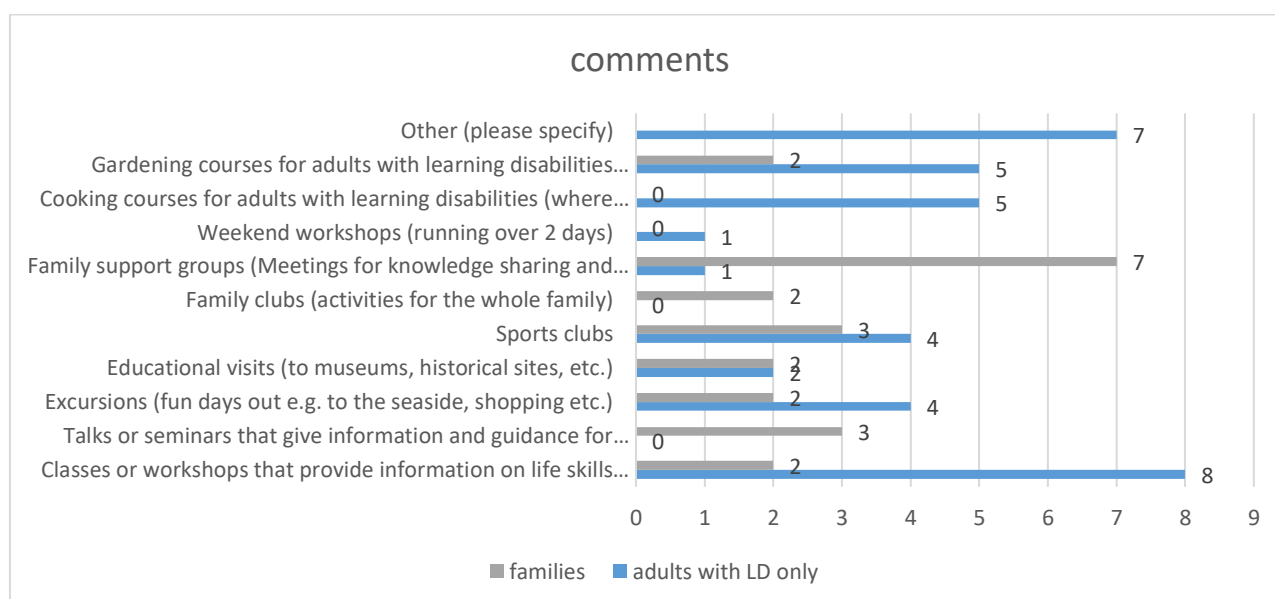
- crucial that environment should take into account accommodate sensory needs too engagement with an audience wider than learning establishment, e.g. community, volunteers, businesses, schools and colleges
- Music Refreshments Mindfulness and meditation
- Nice to have a safe environment away from others. Home would be good as familiar. Have others around to create social aspect to the work being done.
- Very important. We use art exhibitions mostly to showcase learner's work. Cookery book -our tutor puts together a recipe book based on all they have covered in class over the year. The learners get to take this home.
- If the benefits can be seen at the place of learning this is more likely to be followed through at home.
- For the project I run environment is key. We have a Employment Officer from the DWP onsite on a Monday and she is able to better engage with people through gardening then in the office where many of our clients have said they feel anxious and unwelcome. The allotment has been created by clients and ownership of the site is key in them feeling at home and able to engage in learning.

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## PART 2: QUESTIONS FOR THE WHOLE FAMILY

### Q1: Which educational activities does your family participate into in order to support your AFMID?

Most activities are primarily for adults with LD only apart from family support groups and family clubs which are specifically aimed at whole families and educational visits which are seen as shared activities.

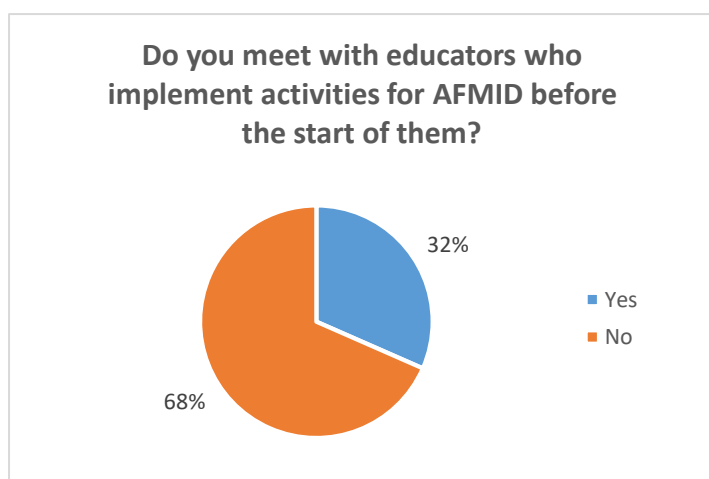


Comments

- 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.

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## Q2: Do you meet with educators who implement activities for AFMID before the start of them?



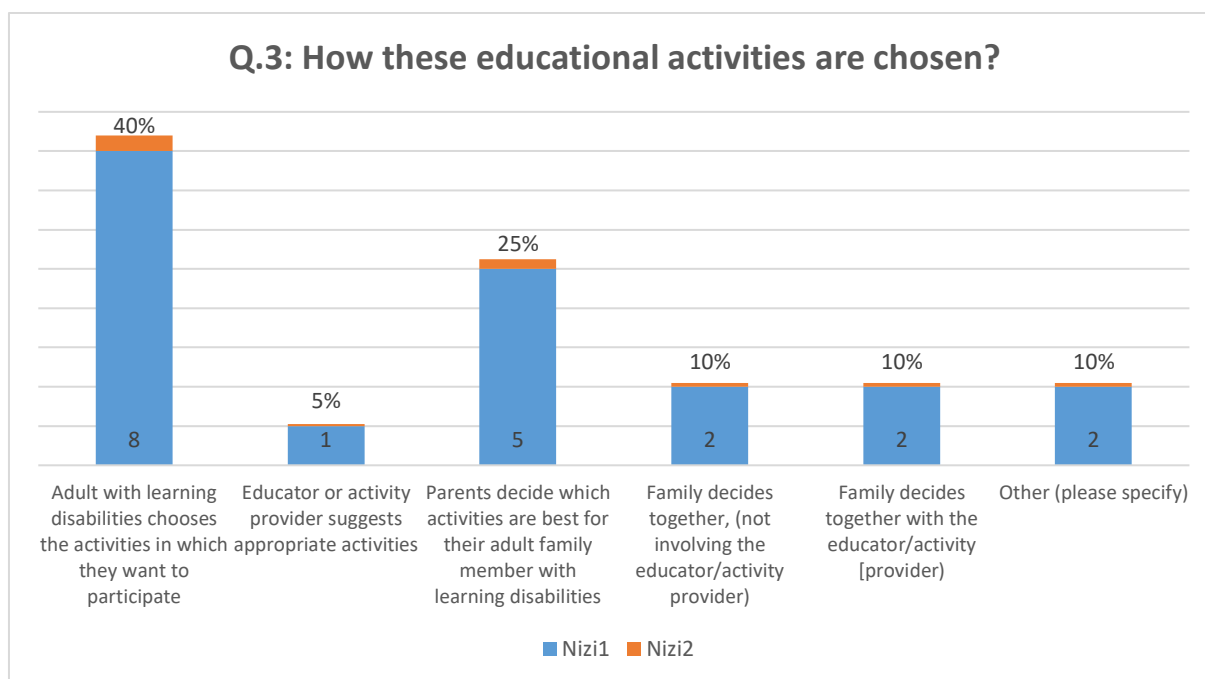
Although the majority of families do not meet directly with educators, there may be secondary discussions with support workers or organisations to identify options for the coming year. In some cases the AFMID attends organisations which offer a variety of different unspecified weekly activities. One participant responded that this

question was irrelevant since there were no activities available in their area.

### Q 2.1: How often?

None of the respondents reported a frequency of meeting with educators. In some cases, they reported was an annual meeting to plan attendance for the coming year. Others reported that they might attend the community group/organisation to decide if it was an appropriate place for their AFMID to attend but did not discuss specific activities, just the general kind of things that might be done.

### Q.3: How these educational activities are chosen?



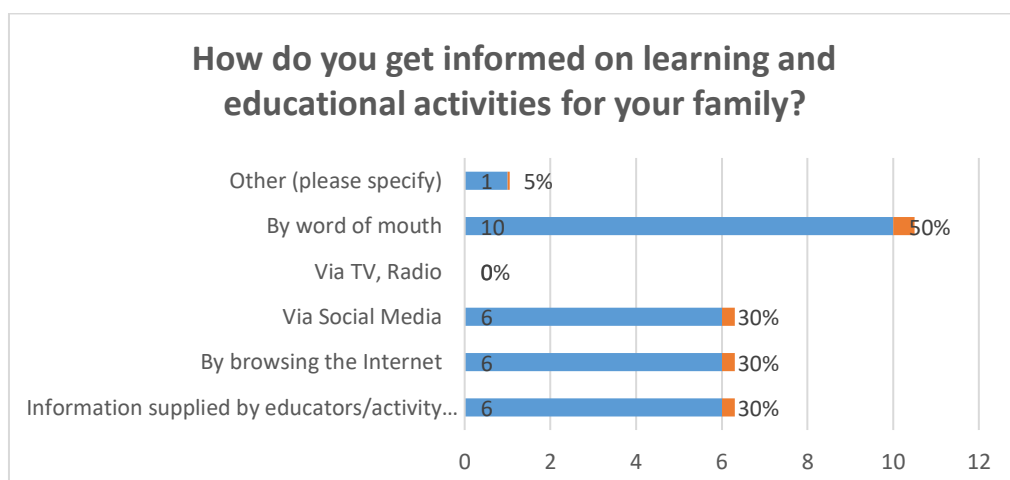
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## Other

- The education package is supplied by a group called Bedazzle paid for by the LA
- Aren't any to choose from. Nothing available so this question doesn't apply.

In general, the AFMID decides on the activities that they want to attend or the parents decide. It is likely that the parents decide when the AFMID does not have the capacity to make decisions themselves. There is little input from the educators (which confirms Q2 – educators are generally not consulted. This is probably since the education and activities are not formalised but provided by community organisations?

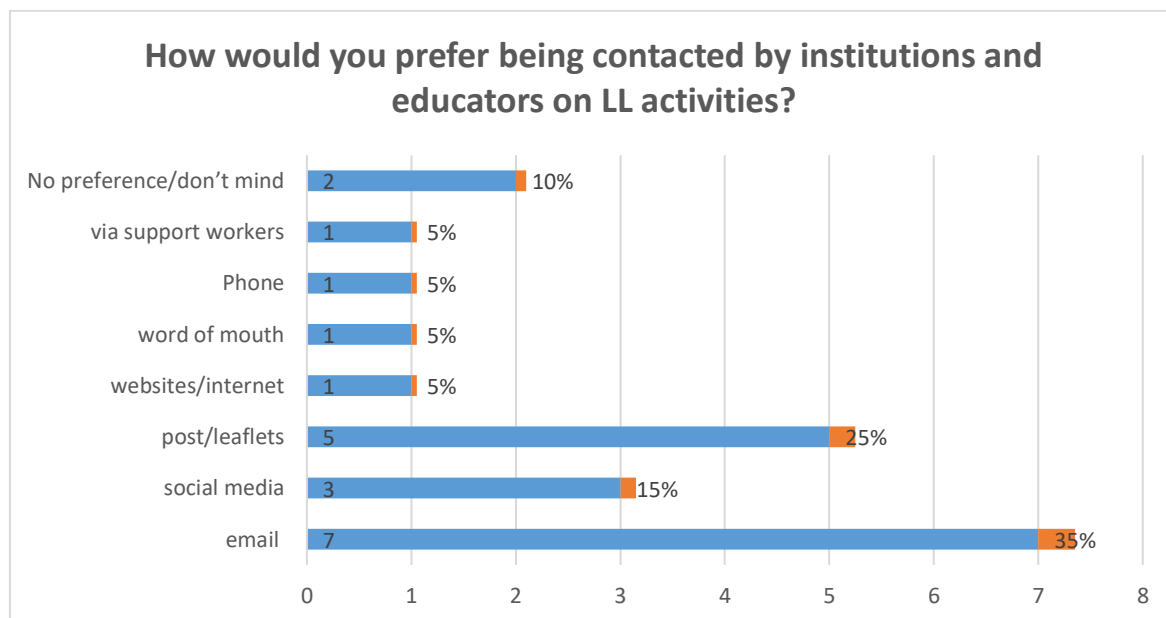
## Q4: How do you get informed on learning and educational activities for your family?



The main route for information reported by respondents was word of mouth. Other routes included information from educators (mail shots, posters, leaflets etc.) and social media/internet. One respondent reported that they get information from their local authority (local government).

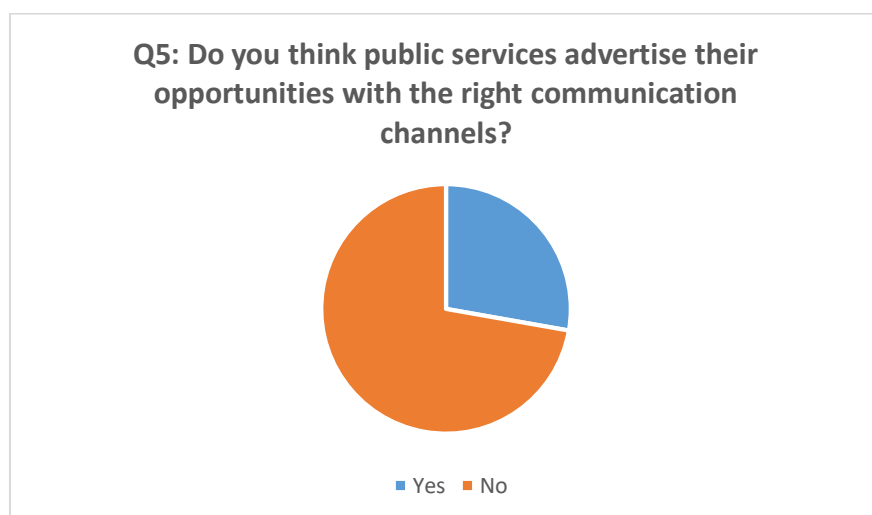
**Q4bis: How would you prefer being contacted by institutions and educators on LL activities?**

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Email and via post/leaflets were the preferred way of being contacted. One respondent said they would like to have an email to themselves and a leaflet or printed material (easy read) for the AFMID.

**Q5: Do you think public services advertise their opportunities with the right communication channels?**



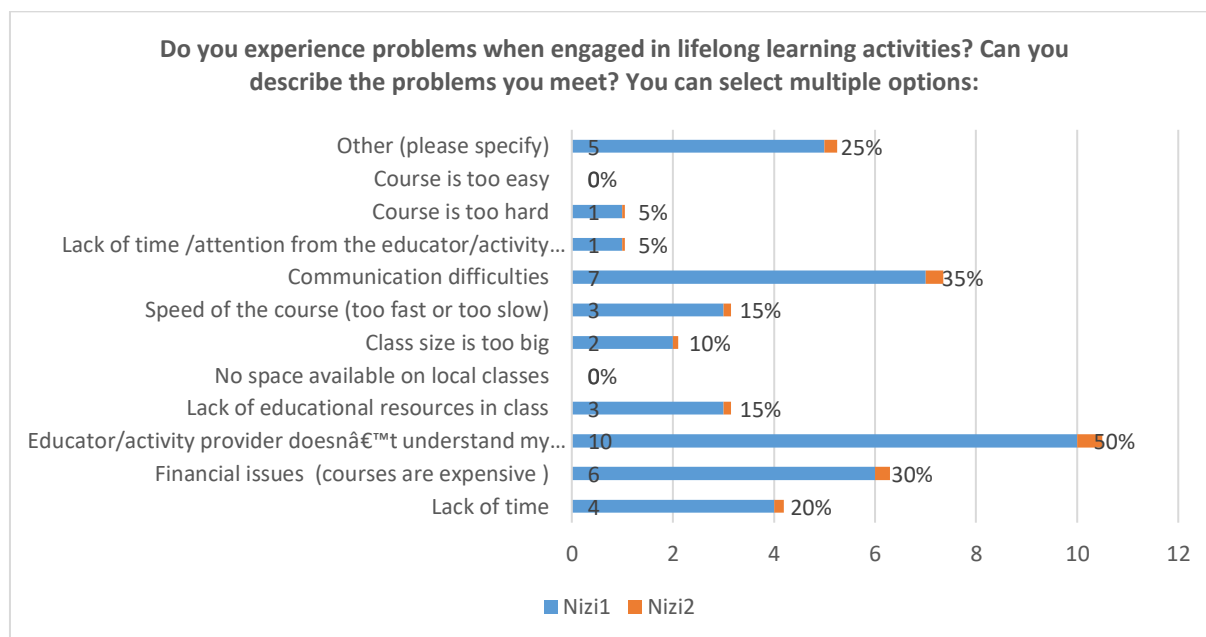
**Comments**

- Haven't seen any services advertising so this question doesn't apply

- People with L.D. tend to tell each other about places they can go to
- Difficult to say....
- Sometimes they do but more often than not we find out via word of mouth
- Should be advertised in all ways
- They could pass on information to care providers in their local area and local LD social care services for families with LD members living at home
- It's quite hard finding activities and many exclude family participation. Families are regarded with disdain by the local authority (local government organisation) and professionals
- I work at the local library. We have a lot of enquiries about services available or learning disabilities. Hampshire county council have Connect to support service we access online but not many people know about it

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**Q6 Do you experience problems when engaged in lifelong learning activities? Can you describe the problems you meet? You can select multiple options:**

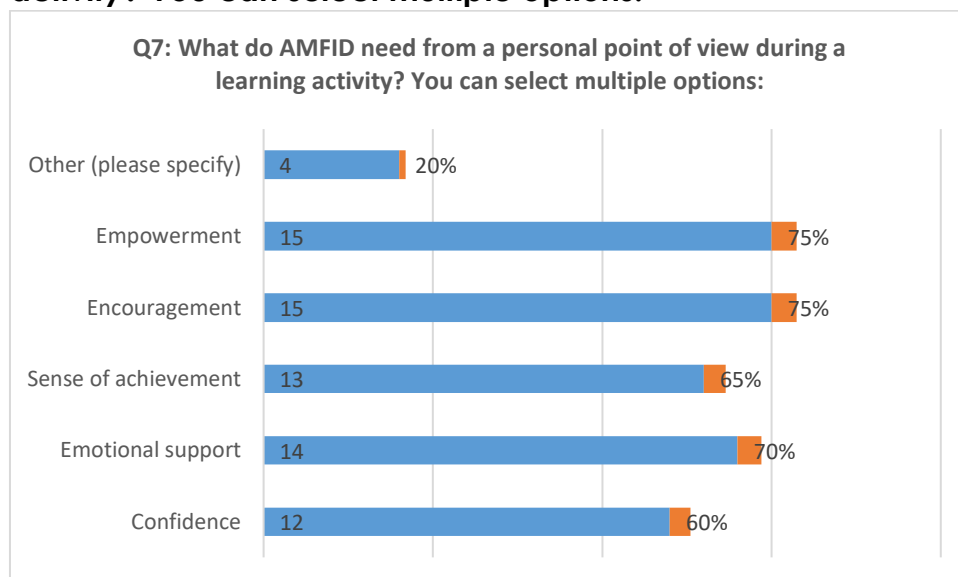


Main issues reported were educators not understanding needs and communication difficulties. Financial issues and lack of time were other challenges. Other issues include

- Transport
- No courses or awareness of anything available at all to attend.
- Lack of support
- Not many suitable classes exist

One respondent replied that they had no issues and educators were already doing enough.

**Q7: What do AMFID need from a personal point of view during a learning activity? You can select multiple options:**

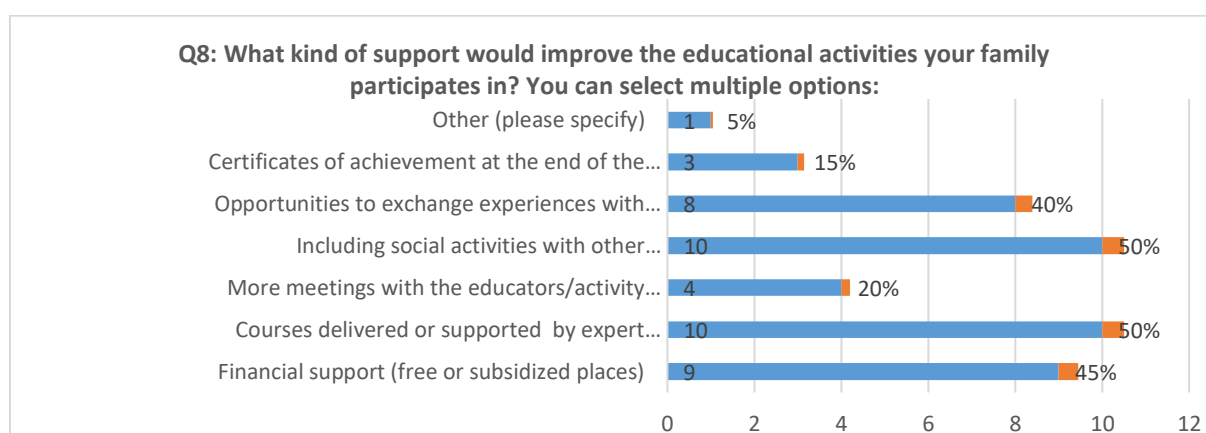


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Respondents rated all of these factors as similarly important with empowerment and encouragement as the most popular. Other suggestions included

- Money
- Plenty of time and no pressure to achieve anything from it if they don't want to. Choices.
- Learning that is accessible and tailored to each person
- A real understanding of their individual needs rather than being lumped together in categories like autistic.

**Q8: What kind of support would improve the educational activities your family participates in? You can select multiple options:**



The majority of families thought that including social activities with other families and having courses delivered or supported by experts would best improve the educational activities. Financial support and opportunities to exchange experience with others were the next most important factors.

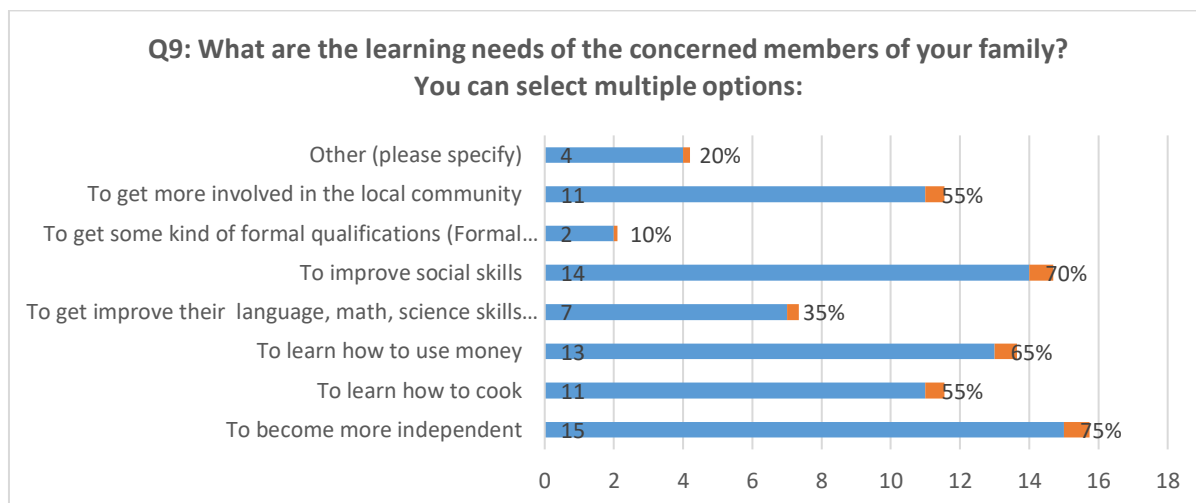


## Comments

- A real understanding of a person's disabilities would be really helpful. The dance class my daughter goes to is much too difficult for a lot of the people there even though it is aimed at people with disabilities

## Q9: What are the learning needs of the concerned members of your family? You can select multiple options:

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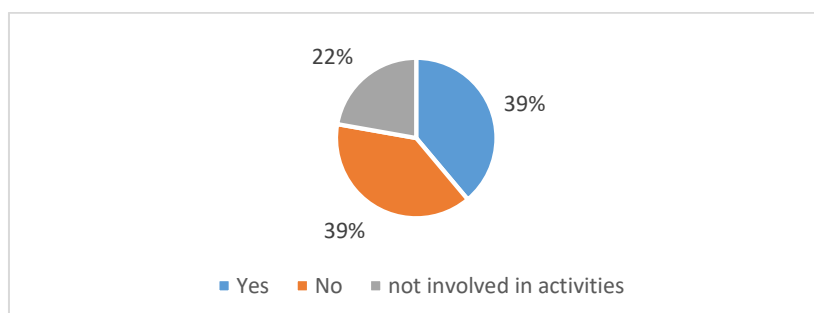


The main learning needs are independence, social skills and community involvement. This makes sense in context of the general move to enable AFMID to live independently in the community (as does the importance of financial and cooking skills) qualifications and functional skills were seen as less important. Other needs mentioned relate to being able to do and feel like any other member of society.

## Other needs

- To make friends maybe even form relationships with same/opposite sex.
- To be given a chance in the workplace
- To feel wanted and like other young lads xx
- To be accepted as human beings and not some weird thing

## Q10: Are you satisfied with the services you get from the institutions where your AFMID is included (school, group home, associations etc.)?



### Q11: If no, please, explain how they could improve:

- There is nothing in my area for my son to do
- Need more services which work to the Social Model of Disability
- They need to be run by tutors who have the imagination and understanding of what a person with LD needs

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## 5.6 QUESTIONNAIRE SUMMARY

### The educators

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

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

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

### The families

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

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

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

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

## 6. CONCLUSIONS

### EDUCATOR QUESTIONNAIRE

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

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

As reported by educators in all partner countries, the main channels of communication used with families with AMFID are over the phone or

personally; most adopted methods by respondents are adapted communication, peer and volunteer support.

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

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

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

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

## **FAMILY QUESTIONNAIRE SUMMARY**

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

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

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

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

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

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

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

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

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

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

## 7 ANNEX

### Questionnaires for educators

The following questionnaire is anonymous. Results will be used only for the needs of the project "Family Education "MeTURA – back to the roots". The project – funded by the **Erasmus + Programme, Key Action 2: Strategic Partnership | Adult education** - is the result of the partnership of organizations coming from 4 countries (Slovenia, UK, Italy and Croatia) and it will develop innovative ways on how to bring education closer to home for families with their members affected by intellectual disorders.

#### INSTRUCTIONS FOR FILLING OUT THE QUESTIONNAIRE

When answering, choose one option or write down your own answer, or circle more answers, if it is written so. If you have any further questions you can contact Dario Ferrante, [dario.ferrante@danilodolci.org](mailto:dario.ferrante@danilodolci.org)

#### General Information:

1. Are you:

|                          |        |
|--------------------------|--------|
| <input type="checkbox"/> | Male   |
| <input type="checkbox"/> | Female |

2. How old are you?



|                          |         |
|--------------------------|---------|
| <input type="checkbox"/> | 18 – 25 |
| <input type="checkbox"/> | 25 – 30 |
| <input type="checkbox"/> | 30 – 35 |
| <input type="checkbox"/> | 35 - 40 |
| <input type="checkbox"/> | 40 – 45 |
| <input type="checkbox"/> | > 45    |

3. how many years of experience (formal and non-formal) do you have working with families with AFMID?

|                          |               |
|--------------------------|---------------|
| <input type="checkbox"/> | No experience |
| <input type="checkbox"/> | From 1 to 5   |
| <input type="checkbox"/> | From 5 to 10  |
| <input type="checkbox"/> | More than 10  |

4. If you're interested in the next phases of the project, please, leave your contact here below:

### Questionnaire

**1. Is it easy to get in touch with families with AMFID?**

- Yes

- No

**1.1 If no, what are the main obstacles in this communication?**



**2. Which are the main channels of communication do you use with families with AMFID?**

- Over the Phone
- Mail
- Social media
- Personally
- Other:.....

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**3. When AFMID is included in your organization, do you perform any kind of meeting / interview / conversation with him/her family to determine their educational need/preference?**

Yes

No

**3.1. If yes, why do you think it's useful? You can select multiple options**

- To get information on their needs
- To have insights on what activities they would like to join
- To know how to motivate them to join activities
- Other:.....

**4. What kind of methods do you use in your activities for get AMFID involved?**

- Adapted communication
- Peer support
- Volunteer support
- Teaching aids
- Club House International
- Picture Communication System
- Picture Exchange Communication System
- Other:.....

**5. What kind of features in the communication process with AMFID do you think an educator should have to successfully work with them? (multiple choices possible) – scaled questions (1/5)**

- Open-mindedness
- Listening



- Mediation
- Being firm
- Cohesion and clarity
- Friendliness
- Confidence
- Empathy
- Respect
- Patience
- Emotional intelligence
- Other:.....

**6. Do you experience problems while you implement lifelong learning activities? Which problems do you meet when you work with them?**

- Families are not responsive
- It's hard to get in touch with them
- They are not interested in participating in the activities
- Families are responsive but AMFID is not
- AMFID is responsive but family is not
- Other:.....

**7. How do you engage to resolve problems (e.g. motivational, behavioural, emotional) of the AMFID when they're engaged in lifelong learning activities?**

- I involve other family members to solve the issue
- I deal with the issue only with the AMFID, not including the family member
- I involve families and AMFID
- Other:.....

**8. As educator, what kind of support would help you to improve during the educational activities that you deliver?**

- Additional tools
- Training on new methodologies
- More support (i.e. mentors)
- More educational resources

- More motivational techniques
- Other:.....

**8.bis Which motivational techniques do you find effective when working with AFMID?**

.....  
.....

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**9. Which are the reasons, in your opinion, that the AFMID and families are not included in activities provided for them:**

- Lack of time
- Lack of motivation
- Transportation difficulties
- Lack of tailor-made activities
- Lack of financial support
- Personal difficulties (or health-related issues)
- Other:.....

**10. Do you think that if the activities were carried out in the home environment, the AFMID and families would be more keen to practice the activities?**

- Yes
- No

**11. What is in your opinion an effective communication strategy when you work with families with AMID?**

**12. Do you think there is a risk of overburdening families with too much information on institutional forms of lifelong learning?**

- Yes
- No

If no, how can it be prevented?

**12.bis If yes, what kind of content should be provided in communicating about LL activities to families?**

13. Based on your experience, do you have tips for implementing LL activities for families in their own home environment?

14. How much is it important a positive response and motivation from the environment when involving families of vulnerable adults in lifelong learning programmes? How would you promote it?

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## Questionnaires for families

The following questionnaire is anonymous. Results will be used only for the needs of the project "Family Education MeTURA – back to the roots". The project – funded by the **Erasmus + Programme, Key Action 2: Strategic Partnership | Adult education** - is the result of the partnership of organizations coming from 4 countries (Slovenia, UK, Italy and Croatia) and it will develop innovative ways on how to bring education closer to home for families with their members affected by intellectual disorders.

### INSTRUCTIONS FOR FILLING OUT THE QUESTIONNAIRE

When answering, choose one option or write down your own answer, or circle more answers, if it is written so. If you have any further questions you can contact Dario Ferrante, [dario.ferrante@danilodolci.org](mailto:dario.ferrante@danilodolci.org).

#### General Information:

1. How many people in your family are affected by intellectual disorders?

2. Do you want to leave your contact for future development of the project?

## Questionnaire

### 1. Which educational activities does your family participate into in order to support your AFMID?

- Seminars
- Lectures
- Excursion
- Guided visits of institutions
- Sport games, activities
- Club of parents, kids, families
- Meetings for exchanges experiences among families
- Weekend seminars
- Cooking workshops
- Gardening workshops
- Other:.....

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### 2. Do you meet with educators who implement activities for AFMID before the start of them?

Yes  
No

#### 2.1. If yes, how often?

.....

### 3. How these educational activities are chosen?

- AFMID chooses the activities in which he/she wants to participate
- The educator suggests the activities
- Parents decide which activities are good for their AFMID
- Family decides together, not involving the educator
- The family decides together, involving the educator
- Other:.....

### 4. How do you get informed on learning and educational activities for your family?

- Educators/institutions inform us
- Internet
- Social Media
- TV, Radio
- Word of mouth
- Other: .....

**4.bis How would you prefer being contacted by institutions and educators on LL activities?**

.....  
.....

**5. Do you think public services advertise their opportunities with the right communication channels?**

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- Yes

- No

**6. Do you experience problems when engaged in lifelong learning activities? Can you describe the problems you meet? You can select multiple options:**

- Lack of time
- Difficulty in accessing the activity financially
- Lack of information shared with the educators
- Lack of educational material
- Too many participants
- Class size
- Speed of the course
- Communication difficulties
- Lack of time from educator
- Level of the course (too high)
- Level of the course (too low)
- Other:.....

**7. What do AMFID need from a personal point of view during a learning activity? You can select multiple options:**

- Confidence
- Emotional support
- Sense of achievement
- Encouragement
- Empowerment
- Other:.....

**8. What kind of support would improve the educational activities your family participates in? You can select multiple options:**

- Financial support to participate in more educational training
- Support from an expert in the field which can help to facilitate the learning activity
- More meetings with the educators to achieve better the learning objectives
- Socialising with other families
- Exchange of experiences

- Final certification
- Other:.....

**9. What are the learning needs for the concerned members of your family?**

**You can select multiple options:**

- To become more independent
- To learn how to cook
- To learn how to use money
- To get knowledge on language, math, science through informal activities
- To improve social skills
- Formal recognition of new acquired skills
- To get more involved in the local community
- Other:.....

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**10. Are you satisfied with the services you get from the institutions where your AFMID is included (school, group home, associations etc.)?**

- Yes
- No
- Not included

**11. If no, please, explain how they could improve:**