



# A COMPASS TO DEVELOP SERVICES FOR FAMILIES WITH DISABILITY

YAID Final Report

“YAID - Young Adult with Intellectual Disability: an European Learning Partnership for a new approach to the family system” is a project founded by the Grundtvig - Life Long Learning Program 2007-2013.



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# SUMMARY

## Summary

THE PROJECT	1
PARTICIPANT ORGANIZATIONS	2
GAP - Italy	2
Viltis - Lithuania	3
Enable Works - Scotland	4
Bubamara- Croazia	5
THE PROJECT TEAM	7
GAP - Italy	7
Viltis - Lithuania	8
Enable Works - scotland	9
Bubamara - croatia	10
THE ACTION-RESEARCH	12
Scotland	13
Italy	14
Croatia	16
Lithuania	17
Main findings of the research	19
VISITS OF THE SERVICES IN EACH COUNTRY	21
Scotland	21
Lithuania	23
Croatia	25
Italy	27
A COMPASS TO APPROACH THE FAMILY SYSTEM	29
CONCLUSIONS	31
Acknowledgments	34

## THE PROJECT

“Y.A.I.D. Young Adults with Intellectual Disability: an European Learning Partnership for a new approach to the family system” is a project founded by the Grundtvig - Life Long Learning Program 2007-2013. The project started with the recognition of the transition to adulthood as a critical period influencing the quality of life of the families of persons with intellectual disabilities exposing them and their family members to a progressive social isolation. In the field of intellectual disability in many European countries there is a lack of services that operate on the transition to adulthood. For this reason the YAID project has involved a group of organizations based in Italy, Croatia, Lithuania and Scotland in a transnational action research to identify the main problems faced by young adults with intellectual disability and their families. The action research has involved 60 families of young adults with intellectual disability: 15 families has been involved in each country.

The staffs of the partner organizations have meet each other in a series of 6 meetings in which the participant organizations have explored and analysed the different local contexts visiting the services for persons with intellectual disability they run. Furthermore, during the meetings the action research data have been discussed. The final result of the project is a “compass”, a set of criteria to develop effective projects and services for the young adults with intellectual disability and their families. The “compass” is addressed to all the organizations working in the field of disability realizing projects and services for the families of young adults with intellectual disability. The results of the project have been collected in a site built for the dissemination to all the interested persons and in particular for members of persons with intellectual disabilities. Furthermore a series of dissemination conferences of the project results have been organized to promote a critical reflection between different stakeholders on the main problems faced by the families of young adult with intellectual disabilities.

## PARTICIPANT ORGANIZATIONS

### **GAP – ITALY**

The coordinating organization Associazione di Promozione Sociale Gap was founded in 2012 by a group of psychologists. Main aim of the organization is the implementation of innovative projects and services for development of the quality of family of the social groups at risk of exclusions. GAP work between the territory of the VII Municipality of the city of Rome and the rural area of the Roman Castle close to it.

GAP is still a small association, which is growing and working to transform its projects in stable services. The association has a management team made by 3 persons that plays a coordinating role of the implemented projects. Gap runs different psychosocial projects and services addressed to the persons with disabilities and their family members such as action research activities, personal assistance services for persons with intellectual disabilities and consultancy services. Furthermore GAP provides organizational consultancy services for social and sanitary agencies providing services in the field of disability. GAP projects and services are realized in partnership with a network of third parties at local and European level. The collaboration with other stakeholders is very important as, within the well established welfare system of the country, GAP usually works for implement services supporting the ones already existing.

In addition to the YAID project, GAP is currently implementing 3 projects. The first project called “advice for navigation” is an organizational consultancy project developed on the commitment of the “Service for the Adult Disability” of one of the Local Sanitary Agency of Rome. Aim of the project is to train the staff of this service (nurses, social workers and educators) to develop psychosocial competences to analyse and treat the demands of their clients: mainly parents of adults and young adults with disabilities. The second project is a social agricultural project called “Made In Pizzuto”. The project started in 2012 with the direct commitment of 3 families and is now financed by the social department of the Lazio Region. The main goal of the project is to involve a group of family members together with their sons or daughters with intellectual disabilities in developing a common social enterprise. The role of the GAP psychologists in the project is to build a working group and to facilitate the interaction between the participants. The third project is an action research project called “Enea Network” and founded by the Social Department of the Lazio Region. The project is aimed to exploring and understanding the main problems related to the care and the assistance of the elders.

# PARTICIPANT ORGANIZATIONS

Another aim of the project is to build a case management service based on the collaboration between the various stakeholders involved in the care and the assistance of the elders such as psychologists, doctors, social workers, guardians, family members.

The problem of a lack of coordination and case management between different services is in fact a crucial problem in Italy.

## **VILTIS – LITHUANIA**

The partner organization Viltis Welfare Society for persons with disabilities was founded in 1989 in Vilnius, Lithuania, on initiative of doctor Ddainius Puras and a group of parents of persons with disabilities who gathered together with mental health specialists. Since its foundation Viltis worked to build effective services for the persons with disabilities and their parents. Since 2004 “Viltis” is an association, that consists of 53 branches of Lithuanian welfare society for persons with mental disability located all over Lithuania. The main aim of the organization is to unite the families who have children with mental disability and psychiatric problems and to set addressing issues related to care, education, employment, recreation and sport.

Nowadays Viltis associated members run different services for persons with disabilities and their families such as day care centres, family support centres, special transport services, parents support groups, summer camps for persons with disabilities and their parents. In 1990 society “Viltis” started developing services for the education of persons with disabilities, participating in setting up of training centres, special schools and classrooms for children with disabilities. A few years later, following renovated laws and guidelines, Viltis started to set up school services also in mainstream group or class, following the mainstream curriculum, but with special methods applied or following a modified mainstream curriculum or an alternative curriculum or individual education plan.

Their goal is to ensure successful implementation of the UN Convention on the rights of Persons with Disabilities, contributing to protection and monitoring of people with intellectual disabilities and their families, to initiate development of complex assistance mechanism in all regions of the country, to be involved in policy formulation and decision-making processes. Society “Viltis” cooperates with the public and government institutions, local municipalities, foreign partners, other organizations working in this field and private persons on long-term legislative program seeking to create a new concept of disability based on principles of human rights and self-advocacy. Viltis

# PARTICIPANT ORGANIZATIONS

together with the ministry of Social Affairs is member of the working group monitoring the implementation of the closing of the mental institutions in Lithuania. Viltis organizes seminars, training courses for professionals, parents and volunteers working with disabled persons and edits the Magazine "Viltis".

Society "Viltis" is a member of inclusion Europe and Inclusion International; since 2013 it is a member of Lithuanian Disability Forum, a member of NGO coalition "For the Rights of Children", "Mental Health 2030" Coalition, member of the Council on Disability affairs at the Ministry of social security and labour of the Republic of Lithuania. The society "Viltis" is deeply involved in the de-institutionalization process going on in Lithuania and in the neighbouring Eastern European countries, Belaruse, Ukraine, Moldova, Kazakhstan.

The actual goal of the organization is the setting up of respite services for families raising and caring persons with mental disability, personal assistance services and employment services for persons with mental disabilities.

## **ENABLE WORKS - SCOTLAND**

The partner organization ENABLE Scotland was founded in Glasgow by a group of 5 parents in a meeting in Glasgow Corporation's Education Offices on 9 April 1954. Main aim of the organization is to help parents to get better services for their children who had learning disabilities.

Nowadays ENABLE Scotland is the largest organization in Scotland of and for children and adults who have learning disabilities and their families with a network of around 4000 members in 47 local branches as well as 500 national members throughout Scotland. ENABLE Scotland is also an important care service providers in Scotland employing more than in 1000 persons for the implementation of services for persons with mental disabilities and their parents. Since its foundations Enable has organized day centres, hostels, day centres for educations and training of persons with disabilities, residential homes, small size family home for whom moving out from the closing mental hospitals and short break family support services.

ENABLE WorkS, the department of ENABLE Scotland involved in the YAID project, organizes services for transition to work and employment of persons with intellectual disabilities employing 100 staff. The staff is divided in five working team organized on geographical basis with local coordinators coordinated by a manager at central level.

# PARTICIPANT ORGANIZATIONS

The working team implementing the youth project instead manages projects and services in the whole country.

ENABLE Works runs youth services, transitions services, government programmes, supported employment services and social enterprises. The youth services manage youth groups that support young people who have learning disabilities to engage in social activity with people their own age, to develop social skills, take part in community and become self advocates on issues that matter for them. Transitions services deliver embedded employment services in over 70 schools and 17 colleges across Scotland – supporting young people with learning disabilities to make the transition into employment after school and college. Through the British Government’s Work Choice programme for adults who have a learning disability and the Scottish Government’s Employability Fund, ENABLE Works runs services to support people aged 16-24 into employment. In particular the supported employment service provides employability services to adults who have learning disabilities in partnership with social work services in Glasgow, Inverclyde, Edinburgh and Aberdeen. Additionally within the Re-Connect programme, ENABLE Works runs service to support ex-Remploy workers who have a range of disabilities back into employment.

Finally ENABLE Works manages two Social enterprises: Darling’s Coffee Shop in Arbroath and Hazeldene Horticulture in Kilwinning where persons with disabilities are trained to develop employability skills in a real working environment before supporting their transition into further employment.

## **BUBAMARA- CROAZIA**

The Association of People with Disabilities “Bubamara” is a non-governmental, non-profit organization dedicated to improving the quality of life for people with physical and mental disabilities and their families. Bubamara works to promote the inclusion of the persons with disabilities in the field of education, health, social care and employment, self- participation, raising public awareness for the rights of people with disabilities, lobbying for changing the legislation and its implementation. Bubamara has been founded in 1984 by two persons with physical disabilities and parents of a persons with mental disabilities. The organization actually works in the area covering the city of Vinkovci, Vukovar, Županja, Ilok and Otok as well as the surrounding villages from Eastern Croatia and is divided in four sections dedicated to: intellectual disabilities, physical disabilities, muscular dystrophy, cerebral palsy. Each section has it’s own coordinator that together with other four members made the board of directors of the

## PARTICIPANT ORGANIZATIONS

organization. The name of the organization highlights part of his history. Bubamara in fact means “ladybird”: the logo of the national lottery that was the main founders of the organization at the time of its foundation. Since 2009 the organization was mainly financed with donations of the national lottery and the Ministry of the Social Policy. After the entering of Croatia in the European Union a process of internationalization started and the organization become applicant of several agencies incrementing the number and type of services offered to its members. Many projects of the organization started with the founding of European Programs and ten continue with the committing of the Ministry of Social Policy.

In particular Bubamara runs a day centre in Vinkovci founded by the Ministry of Social Policy. The centre organize mainly creative laboratories and socialization activities such as karaoke. Another project run by Bubamara is a personal assistance service for persons with physical disabilities addressed to 60 persons and an assistance service for persons with physical and intellectual disabilities at school employing 111 assistants. The personal assistance service provide not only practical help for persons with disabilities but is addressed also to develop the quality of the social life and make attention to organize opportunity of socialization for the assisted persons. At school instead the assistance service is not related to teaching tasks but to integrate the persons with disability in the school and in the classrooms.

Furthermore the organization runs a mobile team service to assist people with disabilities living in isolated rural areas as the majority of the villages of the region. Each person can be assisted for whatever could be their problems and the mobile teams make a round in each village once a week. As an example the mobile teams, made by different professionals, provides help to hygienic and medical assistance, administrative assistance, paying the bills or shovel the snow in the winter if it's necessary. Other projects implemented in the last year have been a greenhouse project engaging persons with disabilities in growing up plants, English and informatics courses for persons with disabilities, sports project and socialization trips. Finally each year Bubamara organize a concert for raise money for its activities of the association that represents a important annual event for the whole town of Vinkovci.



## THE PROJECT TEAM

### GAP – ITALY



**Felice Bisogni**, president and co-founders of APS GAP, is the coordinator of the YAID project and of some of the projects of the organization that are currently under implementation. He is a clinical psychologist, a PhD in Social Psychology at the “Sapienza” University of Rome with a thesis on the daily problems faced by the families of young adults and adults with intellectual disability and their relationship with the services for disability. His research interests have mainly been focusing on the individual-context relationship, cultural and organizational studies in both clinical and psychosocial field. In particular he is expert in realizing action-research addressing the topic of the quality of life of social group at risk of social isolation. Furthermore he collaborates, with a service for adults with disability of one of the Local Sanitary Agency of Rome as a organizational consultant and he realizes psychotherapy’s interventions with young adults, adolescents and their family members.



**Stefano Pirrotta** is one of the co-founders of APS GAP and actually the coordinator of an action research project called “Enea Network” aimed to understand the daily problems and the demand of services of not self-sufficient elders and their families. He is a clinical psychologist and Psy.D. student at the SPS School of Psychoanalytic Psychotherapy and he collaborate, as a organizational consultant, with the a service for adults with disability of one of the Local Sanitary Agencies of Rome. He also collaborate with the research centre CERI of the Sapienza University of Rome realizing research aimed to explore the perception of the low carbon technologies and other environmental topic by the citizens. His research interests have mainly been focusing on the individual-context relationship, cultural and organizational studies in both clinical and psychosocial field. Furthermore he realizes psychotherapy's interventions.

## THE PROJECT TEAM



**Silvia Policelli** is one of the co-founders of APS GAP. She is a clinical psychologist and Psy.D. student at the SPS School of Psychoanalytic Psychotherapy. She collaborates with the Prevention and Risk Protection Service at San Filippo Neri Hospital in Rome in the field of workplace well-being, health promotion and assessment of clinical and psychosocial risk. She deals with training and support of healthcare workers, aimed at promoting the relationship between healthcare and citizens. Her research interests have mainly been focusing on the individual-context relationship in hospital setting, in clinical and psychosocial field.

### VILTIS – LITHUANIA



**Dana Migaliova**, is the head of Viltis, the leader of the organization since 1996, board member of Department for the Affairs of the Disabled under the Ministry of Social Security and Labor of Lithuanian Republic. She actively participates in international activity in the field of Human Rights protection, national and international workshops, training programs with the East and Central Europe, project activities, TV and radio programs on issues of disabled persons, work with volunteers and parents. She has been awarded “Human rights herald 2011”, the Lithuanian State Award and the medal “Order for merits to Lithuania” in 2013.



**Natalija Olesova**, program manager and responsible for foreign relations of „Viltis“ , she works to keep and develop contacts with partners, foreign embassies in Lithuania, organizations working in the field of mental disability and search of new partners. Main duties of Olesova within Viltis regard the project coordination and implementation, mainly with partners from Western and Eastern Europe and the enhancing of fund-raising of organization.

# THE PROJECT TEAM



**Andrius Šleivys** is the manager of a day care centre “Vilties Akimirka”. Since 2007 worked as a physical therapist in day care centre “Viltis”. He evaluates physical activity of a person, defines level of personal self-sufficiency, selects methods taking into account type of syndrome and general state of health, arranges individual physical therapy procedures. Since 2013 Sleivys manages the day care centre program, arranges activities of the centre according to social programs, provision of social services, economic and other activities; he also consults families on social issues, mediates between various institutions and structures, persons with mental disabilities and their families.

## ENABLE WORKS - SCOTLAND



**Jamie Rutherford** manages ENABLE Scotland’s employment and young people’s services nationally. This consists of, amongst others, youth advocacy projects, transitions support in schools and colleges, SDS Employability Fund, DWP Work Choice and supported employment services in 22 local authorities. He launched Scotland’s first Self Directed Support employment service, led the design of an accessible Certificate of Work Readiness and was involved in the Commission for Scotland’s Young Workforce which highlight’s ENABLE Scotland’s schools services. Jamie led ENABLE Scotland’s Transitions to Employment program, which has supported hundreds of college students who have learning disabilities into work and has been recognized by both the Scottish Government and EU as a model of best practice.



**Linda Barnwell** has worked with ENABLE Scotland for almost 20 years. During this time she has gained a vast amount of experience in the field of supported employment. Supporting numerous amounts of individuals to gain and sustain employment, using a number of innovative initiatives and programs. Currently, Linda works with a team of our transition and program cordinators across Scotland, in supporting them to deliver one of our main programs funded by Scottish Government. This program helps

# THE PROJECT TEAM

to develop: independence, interpersonal and team skills, communication and most importantly jobs for over 350 people who have learning disabilities over the period of 1 year. Over the last year, Linda has helped to develop and extend this program too not only develop our business, but most importantly, reach more people with disabilities and support them with their aspirations of securing meaningful sustainable employment for their future.



**Briony Williamson**, with a background in psychology and a masters in occupational psychology, started her career in mental health and community support, before moving on to work on a ENABLE Scotland supported employment project working with further education students with learning disabilities. Briony is now the ENABLE Works Business Manager for Edinburgh and the Lothians and manages supported employment projects based in schools and further education colleges, as well as projects which support adults in the community who have learning disabilities or long term health conditions and helps them to progress into and sustain paid employment.

## BUBAMARA - CROATIA



**Tomislav Velić** is the head of the association of people with disabilities Bubamara since 10 years. Currently a student of social work course. His main activities and responsibilities are the management of the entire organization as well as the organization's applications and implementation of proposals. He is also responsible for overall financial performance of the organization. Due to his experience in project cycle management and in implementation of various project activities he developed a wide array of organizational and managerial skills and given the fact that association's main activities are concerning mainly persons with disabilities he is very experienced and familiar with the issues and specific needs of persons with disabilities.

## THE PROJECT TEAM



**Marija Crnjak** is the secretary and main administrator of the association of people with disabilities Bubamara since the past 15 years. She is currently a student of a social work course. Her main activities and responsibilities within the organization are working with members and their families, many of which are people with disabilities, providing various services aimed to help the people with disabilities and to improve their overall quality of life as well.

Through constant work with members and their families she developed a wide array of communication and managerial skills as well as great sense of compassion towards persons with disabilities and their needs as she has also a physical disability.



**Žana Skejo-Škorić** is the executive director of Bubamara association of people with disabilities for the past 1 year. She is currently a student of a psychology course. Her main activities and responsibilities are: Head of association's project management team for the past 5 years, in charge of writing, applying and implement various projects and proposals aimed to improve the overall quality of life for persons with disabilities and their

families. Due to her great experience in writing and implementing of projects, activities and very good knowledge of English, Italian and Spanish she developed a wide array of skills needed for an effective management of the projects and a good cooperation with partners across Europe. Thanks to her committed approach in working with people with disabilities, she became very familiar with their problems and needs.

## THE ACTION-RESEARCH

The realization of an action research aimed to understand the main problems faced within the families of young adult with intellectual disabilities has been a core part of the project. The main aims of the action research has been to develop a set of intervention criteria to set up innovative projects and services. Each organization has realized 15 interviews: a total number of 60 interviews has been realized during the project. The persons involved in the interviews have been mainly family members of persons with intellectual disabilities. Some interviews have involved also the persons with intellectual disabilities individually or together with their parents or relatives.

All the interviews have been audio recorded. Some of the interviews realized by the Croatian partner has been also video recorded. The main part of the interviews has been realized by the members of the project team. The interviews realized by the Scottish partner organization have been realized by social workers not directly involved in the project team. The interviewed persons are mainly clients of the project and services run by the partner organizations. Interviewing the clients of the partner organization have implied also a check of the service users satisfaction regarding how their daily problems are addressed in the services run by the partner organizations. To realize the interviews has been a complex experience for the interviewers. Sometimes the interview has been transformed into a frank conversation that gave the interviewed persons the opportunity to share their problems, their worries and their hopes for the future. Nevertheless, on the other hand, sometimes the interviews has been hard to be proposed and realized: for some parents and relatives wasn't easy to talk and speak about their problems as well as for the interviewers wasn't easy to listen to them getting in touch with their feeling of anguish and desperations.

In some case the interview has been a surprising experience for the interviewers. As an example in realizing the first pilot of interviews, one of the project team members expressed his astonishment in listening how much the parents of a persons with disability attending his service have to say: "I have recorded for more than one hour and I expected they won't speak more than two minutes". Other members of the project team reported that "some issues emerged from the interviews surprised us and we were quite unconscious about needs and aspirations of parents and persons with disabilities". The members of the project team found useful to realize the interviews in term of achieved knowledge for planning new project and services more targeted on the problems faced within the families of persons with disabilities. The interviews in this sense suggest the

importance of considering the whole families and not just the persons with disabilities as the client of the organization working in the field of disability as well as the importance of training the staff to deal with the demands of the families.

During the kick off meeting the partner organizations decided to realize two sets of 3 pilot interviews for each organization to explore the daily problems faced within the family of persons with intellectual disabilities, their experiences and expectations about the project and services for disabilities. For the last set of 9 interviews a set of questions exploring the expectations about the quality of life of the persons with disabilities they are in touch has been prepared. The questions have explored the factors that have contributed to empower the quality of life of the family, the service needed in regards to the role of the interviewed person within the family and the kind of support asked to the municipalities and the public agencies. Listed below we propose the main results of the interviews in each countries.

## SCOTLAND

The interviewed persons are all ENABLE Works clients accessing the transition services and the supported employment services. The interviewed persons with intellectual disabilities are from 19 to 33 years old. The interviewed family members are parents and siblings. The parents and siblings involved agreed that expectations and the quality of life in the future will depend on the possibility to achieve a paid job and live independently. Having a job represents the tool to be part of the society in a productive way without being dependent on the care and assistance of the family members. Paid job and independence are intended by the interviewees as the signs of overcoming the problems characterizing the life of the persons with disabilities during the childhood. Problems in achieving the steps taken for granted while growing up in different context such as the school and the family, in fact underline the diversity of the persons with disabilities when compared to their peers as their siblings. *“He is so different from his siblings and he feels like he is being left behind in what he will be able to achieve and what he will be able to do”* one interviewed mothers says. Paid job represents as well the sign of having entered the adulthood and of the ability to achieve objectives such as live a life as “normal” as possible. *“Our ambition for A. is to have a purpose in life, to get a job, have a family, a house of his own- a normal life”* another mother says.

# THE ACTION-RESEARCH

On the other hand to work represents an ambitious objectives while also doing ordinary things, such as travelling, many times become a challenge within a family of a persons with disabilities. Society in fact is seen as a dangerous place for persons with disabilities intended as too trustful and weak: *“now he is more independent and can travel on his own, but I worry that he may get into trouble with other people. He is very trusting and people with learning disabilities can be vulnerable to abuse”* one parent says. On the other hand parents many times support their sons or daughters in exploring the context where they live in: *“If he falls, he falls. “If he gets his clothes dirty, he gets his clothes dirty. It's a learning thing. We have always said to J ‘never hold yourself back from anything”* one father says.

Isolation is a common problem for the persons with disabilities and the other family members. The persons with disabilities find difficult to have friends or to participated in groups and activities with their peers. *“He'd do that now if he had a decent friend but there's nobody interested in going with him. He's asked a couple of boys but they don't want to go”* one of the interviewed parents says. On the other hand the parents feel to be isolated within their community and struggle with the local authorities seen as distant and not helpful for their problems. Furthermore parents and the other members of the families feel not to be enough considered and supported by the services. : *“There isn't really any support for families- this is the first time anyone has asked our opinion on services..support seemed to finish when he was 18 and there doesn't seem to be a lot out there for adults”* says a mother. *“Some social groups for parents in the same situation might have been good when she was younger too, so you can all get together and talk about what you are going through”* another mother says.

In this context emerge the importance of the reliability of care service providers that are requested to provide what we called “navigating services”. In this regard the Scottish interviews show that demand of the families seems not be related to the difficulty for all the family members of persons with intellectual disabilities in paving their own way from childhood to adulthood building projects for the present and the future.

## ITALY

The interviewed persons are GAP clients accessing a social agricultural project and other family members of persons with intellectual disabilities belonging to organizations active in the field of disabilities within the area of Rome. The interviewed family members are parents, siblings and cousins of persons with intellectual disabilities. The interviews underline the critical moment represented by the end of school and the lack services for transition to adulthood. During the school the



interviewed parents report the difficulty in dealing with “having a different child”: *“I’m very angry because even at school my child is treated as “special” and cannot attend some activities like the others”* a mother says. A feeling of anger towards the others families and children, perceived as being able to have a “normal life”, emerges incrementing the isolation of the families within their community. During the period of childhood rehabilitative and therapeutic services directed to the persons with disability are delivered: *“services have had a really important impact on our life: nowadays we even can’t imagine ourselves without it”*. On the other hand this kind of services seems not to help the family members recognise their own resources or to be prepared for facing the future after the school: *“Sometimes with the therapist you build a dependent relationship. Your son fall and you immediately call your therapist”* a mother says.

After the school the relationship with other families with a child with disabilities seems difficult due to a common perception of lack of services and resources: *“there are few services open to all so there is a war among the poor peoples to access them”* another interviewed parent says. A common problem for the families is the perception of a social isolation and the feeling of loneliness: *“where I live, I have no relationships; there are no aggregation centre where to go with my daughter”* a mother reports. *“Parents loose connection with friends, with relatives..I remember when my daughter was a child, I was ashamed to go to the park and I remained at home”* another interviewee says. In this context the family members ask to the municipalities and the care service providers to be helped. *“We don’t need a questions-answers relationship with the municipalities. We need someone accompanying us, to feel that we are not lonely that we can share our experience”* a father says. *“Accessible public centre co-ordinating and supporting the families when the school finishes are needed: if not the whole family become disabled”* a mother adds.

Furthermore the relationships within the community seems more difficult when the relationships within the family are difficult. In this regard the interviewed family members express a difficulty in understanding each others. This difficulty appears to be related to the crisis and the behaviours of the persons with disabilities “breaking” the norms and the expectations of their parents. *“The problem is that my brother doesn’t execute the rules and makes mistakes: the only way to give him the rules it’s fear and terror”*. The behaviours of the disabled person, seen as mistake to cancel, seem not to have a meaning within the family context. The extreme consequence is that the whole life of the family risk to become not interpretable: meaningless. In this regard emerge a problem of violence within the family that make difficult for the family members to think

about the meaning of their problems and building some mutual rules to live together. In this regards the interviewed families ask for assistance at home. The interviews suggest that helping the family members in understanding the reasons of the reciprocal behaviours could be an important objective of the services for disabilities.

## CROATIA

The interviewed persons are Bubamara clients accessing the day centre service in Vinkovci and the mobile team service. The interviewed family members are persons with intellectual disabilities and their parents. The interviews with the persons with disabilities shows their ambitions, desires and problems. They want to get married, to have children, to be helpful for their family and their community trough a job. *“To be a construction worker is not a hard job if you you want to work”* a 32 years old man with down syndrome says. *“This ring on my hand means that I'm going to marry my girlfriend when her mother decide to let us do it”*. *“I would like to have a child and a family”* his girlfriend says. *“I'd like to continue to help my parents at home doing the housework”* another girl adds. Furthermore the persons with disabilities ask to be close to their family or to someone emotionally important for them: *“before living independently I need to find a partner not to feel lonely at home”* one of them says. They ask the possibilities to have the power to make ordinary choice: *“I would like to have money and to travel round the world”*. s. Sometimes persons with disabilities seems to be happy of perceiving their life as different to a “normal” one: *“I think would be really tiring to work all day, I prefer epic poems as I do every day, poems about life in general and about love”*. On the other hand some of them seem to suffer for the feeling of being different recriminating against a “blamed past”: *“doctors abandoned me. The therapy killed me”* a man who faced meningitis during his childhood says. Making friendship and building social relationships emerge as one of the most important desirers of the interviewees. This seems often difficult within the local community. Even if some persons with disabilities, especially in small villages, seems quite respected and welcomed many of the interviewee reported to be isolated: *“During the day I go to have a walk, lonely with my dog”* a 22 years old girl says. In this context a day care centre can be a big resource for the possibility to make friendship.

Also the intervended parents identified the activities and services such as the day care as a factor of empowerment of their quality of like. Parents report the difficulties faced during childhood when problems started and the search for a *“never achieved cure”*: *“since he was one years old we went to doctors and magicians but we didn't find a solution*

*for him*” a mother says. Parents reported as well that their problems are changing during the time: *“with the puberty that is crucial for his pathologies the situation started to get worst and with the war he started to have psychological problems and aggressive attitude”* a mother says. Parents generally don't look at residential institutions as a resource to face this kind of problems. The worry for the future after the death of the parents seems to be calmed down thinking that brothers and sisters will substitute them in the role of taking care of the persons with disabilities. At the same time the parents report the ambition for not considering the persons with disabilities just as *“burden or as not capable to plead”* and the hope for their sons and daughters to *“live their life making some decision on their own, participating in the community and maybe getting a job”*. On the other hand the parents sometimes seem to risk to underestimate the competences of their children seen vulnerable and incapable: *“they are not independent you must always be there for them, she is independent in making problems”*. Parents in fact report the fear for their sons or daughter to be in danger while doing ordinary things *“not knowing what is wrong and what is right”* and the shame for the socially unsuitable behaviours such as wearing dirty clothes or accepting presents from strangers. Regarding the services asked for themselves parents 9 parents upon 15 agreed in considering the personal assistance at home as a key for the prevention of the isolation of the family. Finally, personal assistance is seen as the possibilities to have choice and control over the service used.

## LITHUANIA

The interviewees are clients of “Vilties Akimirka” day care service and participants of the summer camps. The interviewed persons are parents of persons with intellectual disabilities with diverse diagnosis from mental retardation to autism, mainly parents of persons with severe form of mental disability. Parents express the problem of understanding their daughter behaviours and interests changing during the time. To start dealing with a “diverse” child since the birth is reported by the parents an important milestone and a critical step. A feeling of displacement and crisis is reported regarding the childhood: *“We did not know what to do with this child”, “my husband was devastated after knowing our child's disability” “It's difficult to understand and become used to the thought that your child is disabled”*. At the same time the problems within the family are reported to change during the time. *“During growing period her behaviour, her needs began to change; it was more difficult to understand what she was trying to say”* a mother says. In particular the interviewed parents stress the request of being helped in communicate with their sons or daughter to understand their behaviours and interests:

*“She began to be interested in knives, forks, scissors and so on and It was always necessary to watch out and not to leave such items in accessible places”.* The request of being helped in dealing with the reciprocal feelings, such as fear and worries within the family to become competent in communicating to each other, seems to be shared by the interviewed parents. *“Our daughter understands that she is a disabled person, she anxiously wants to walk, she is worried about it too much, so it is very difficult for us too”* a mother says.

The interviewed parents express a feeling of guiltiness when doing ordinary things difficult to do for the persons with disabilities: *“we are no longer able to take care of her, we would like to go somewhere but we do not go for solidarity with our daughter”.* In this way the family members start to renounce to attend social events such as going to a restaurant, to a cinema or out for a walk becoming isolated during the time. Within this context the siblings seem to play a big role and seem designed to substitute their parents in the caring role of the persons with disabilities.

The role of municipalities and care service providers and other members of the local community is considered important since the early childhood to start building a path for the future. On the other hand Municipalities and other local stakeholders are often perceived as distant and not helpful leaving the families lonely in dealing with their problems. One of mothers says: *“until our daughter entered Viltis day care centre, nobody helped us; „It seems that the state is hiding everything, trying to hurt u; “Nobody wrote us a letter, nobody told us about the benefit we could have.”* In other cases the welfare system looks like an evaluating agency that assess the moral stature of the family rather than trying to give an help: *“we have passed crossed roads to demonstrate that we are not an asocial family, we are not alcoholic”, - a mother reports.* Centres, providers of care services, public institutions seems asked to show their readiness to understand and to pander the specific situation faced by each family: *“We would like the day care centre to be opened during the weekend or during the night so that we could leave our son for a few hours or days if needed”,* a parent says. A common request from all the interviewed family members is to have services at home at home; To use services at home seems to be seen as a key for providing effective and useful support : *“We would like a person with high pedagogical skills come to our house in the week end or in the afternoon hour during the week before we come back from work. It is difficult for our daughter to go to the day care centre 5 days. We highly require people coming to us”,* a mother says. Fun, opportunity of conviviality and socialization are reported to be also very important and many of the interviewed parents quoted Viltis summer camp service as a good initiative for their

quality of life. Finally, the interviews highlight that the family members of persons with disabilities ask for high qualified professionals competent in to working on problems related to communication and relationship within the family and outside the family.

## **Main findings of the research**

The interviews show that fear, displacement, exclusion, loneliness, guiltiness are significant emotional problems faced within the families of persons with intellectual disabilities. Family members express the difficulty in experiencing new form of relationships with their sons or daughter with disabilities and to take part with fun and satisfaction to the social life within their community. They ask for experiencing different ways of being together to feel less “chained” to each other and to build an alternative to the feeling of reciprocal obligation experienced in their daily life. Services, such as summer camps and day centres are perceived to be useful to let the persons with disabilities go out from home, to get in touch t with other members of their community and to have fun. On the other hand these kind of services seems to facilitate the family members getting in touch with professionals and asking them for help to deal with their problems if it is needed. In this sense the interviews confirm the idea that organizing moments of fun and socialization can be a key tool to improve the effectiveness of the services. Furthermore the realized interviews the family members ask for flexibility to the project and services: they want the project and services to be built for their specific problems. A context where to talk about their own daily problems are required. The interviews show that parents of persons with disabilities and other family members want to participate in the planning of the services to improve their quality. In particular the reaserch suggests the importance of a deeper exploracion of the role an condition of the siblings of persons with disability. Furthermore in the interviews realized in all the partner country the parents express the request of closeness and reliability to care service providers and local stakeholders.

The interviews in fact show that the families are afraid to be left alone and look for reference points to get oriented. Public institution and municipalities implied in the providing of social services are seen as distant not really interested in the problems of the families of the persons with disabilities in all the partner countries. Parents and siblings report problems in understanding how to face and understand several lifelong events: since the discovery/diagnosis of the disability to the transition to adulthood. In this regard the setting up of “case management” services addressed to help the family walking through their lives paving their own path for the present and the future can be

a key tool to improve their quality of life. Parents report the difficulty in understanding the persons with disabilities' behaviours and interests changing during the time. This difficulty appears to be shared also by others members of the local community such as teachers, friends, relatives, neighbours that are often afraid due to the incomprehension of unexpected, unusual or aggressive behaviours of persons. In this regard the research suggests the importance of setting up services aimed to "translate" the meaning of the reciprocal feeling and behaviours within the families and within the different contexts attended by the persons with intellectual disabilities.

Finally the interviews show the desires and problems of the person with intellectual disabilities. Making friendship and building social relationships are perceived as the most important issues by the interviewed persons. The interviewees report the importance of being close to their relatives and of finding a partner to live with. Furthermore the interviews show that persons with intellectual disabilities want to have a job or to take part in useful/productive activities.

Useful/productive activities are seen as an opportunity to overturn the role of eternally assisted persons. Doing domestic activities to help their parents, or riding an ambulance, as an example, give them the chance to be useful for their family and community.

# VISITS OF THE SERVICES IN EACH COUNTRY

## VISITS OF THE SERVICES IN EACH COUNTRY

### SCOTLAND



During the meeting of May 2014 the YAID project we visit the Holybrook special school, in the south of Glasgow. Christopher, one of the ENABLE Scotland transition coordinators guides us in a visit of the institute. Passing the corridor we arrive in the backyard of the institute from where we can see at a little distance an “ordinary school”. Holybrook is in fact a special school that in Scotland represents an alternative device to the “integrated classrooms”: it’s a dedicated and separated place for diagnosed students. Crossing the corridors we encounter the Holybrook students. For some of them, for example the ones with down or autism syndrome, it seems easy to figure out why they are attending a special school. For some others instead it's more difficult. The school students seems to have students from 14 to more than 21 years old: a confirm of the difficulty of the process of transition to adulthood. This is one of the reason why since 2009 ENABLE Works is running transition services within the colleges in Scotland. The school in fact represent a referring point for the youngsters with learning disabilities and their family for many years also after its end.

## VISITS OF THE SERVICES IN EACH COUNTRY

During the visit we meet the school headmaster in classrooms with paper, panels and colours everywhere on the walls. Christopher proposes a game to join with the students: to write down on a paper “a plan of our dreams for the future”. It's an unexpected proposal. Through the game we understand that it's not so easy to define “our dreams for the future”. The main dreams of the YAID project team members are “to improve professional skills and the work condition”, “to have enough money for an apartment in the city centre”, “to have a Ferrari”, “to have another dog”, “to marry”, “to make a family”. On the other hand, between us there is who wants an “house in the wood to pick mushrooms”, who wants to “became a fisherman” or “to go surfing in a sunny island”. Regarding the dreams of the students one of them wants “to work in a multinational fishing company in the centre of Glasgow to be able to go working abroad”. Many of them want “to travel abroad”. After the visit of the school we encounter with Gary, an ENABLE Scotland employment coordinator and Christine: one of the girls he supports in her employment. Christine works in a shop after being trained to sell dresses within one the ENABLE services.

During the meeting in Glasgow of May 2015 we move from Glasgow by train to Arbroath, a town situated on the sea in the north east of Scotland to visited the Darling's Coffee Shop: a social enterprise acting as a training service for persons with intellectual disability. At the Darling's we meet Louise and Keri, two ENABLE Works transition coordinators that explain us their way of working in the service. Within the service, the youngsters clients attend a training course of three weeks to explore their expectation about the job and their skills. After that the trainees are engaged in a six week working experience in the Coffee Shop getting a certificate of “readiness to work”. Then Louise and Keri help them in trying to find another place where to be employed in the open market. The 50% of the trainees usually find a job and the some of the others sometimes come back to the service. Jamie Rutherford explains us some difficulties linked to realize such a service in a small village with less clients than a big city and with a higher unemployment rate. The service started after receiving 1 million pounds grant to implement a multi annual program. Jamie Rutherford underlines the difficulty in maintaining the sustainability of the project and possibility of its closure after the finishing of the funding. In this regard the visits of the services run by ENABLE Works highlights the link between the work and the building of project for the future after the end of the school. This seems one of the new crucial challenge for the organization realizing services for disability in this historical period.



# VISITS OF THE SERVICES IN EACH COUNTRY

## LITHUANIA



During the visit in Vilnius of June 2014 the YAID project team visited the day care centre run by Viltis's associated member "Viltis Akimirka" and "Sviesa day care centre", a public service directly run by the municipality. The day care centres in Lithuania represent one of the community based service intended as an alternative to the 26 mental hospitals and to the 3 institutions for mentally disabled children still active in the country. In the country there are 31000 persons with intellectual disabilities: about 25000 of them live within their families and the others within psychiatric hospitals and other institutions. As Dana Migaliova explains us in "many cases family members are the only responsible for the caring of persons with mental disabilities and that's why families need to have support via the services for the person with mental disabilities".

In this context the activities of "Viltis Akimirka" day care centre are financed by the program for the day care of person with severe complex disabilities. The centre is daily attended by 21 persons: 80 % of the attendants are persons with complex disabilities. The day care centre is located in Vilnius on the ground floor of the building where Viltis has its main office. The centre is made up of several rooms divided up on the "ground floor for clients. Some of attendees join games and creative activities; others rest in the beds and sofas. In the centre there is a kitchen and a room for the kinesotherapy where Andrius Sleivys, a member of the project team, works. The kitchen is very important and represents the common space of the centre where the clients eat together at lunch

## VISITS OF THE SERVICES IN EACH COUNTRY

sometimes cooking their meals. The director of the centre Urate Matulaitienės says: “Clients always have a lot of work to do: to communicate between each other, to go on excursions, make shopping or go to the café to be integrated in the society. We start since 7 am in the morning until late depending on the needs of and requests of parents, but the centre doesn't work during the night”.

“Sviesa” day care centre instead is located in the middle of a nice green residential area composed by small family houses. The director of the centre Urate Tamashauskienė explains that the centre works under a specific welfare program for persons with mental disabilities aimed to improve the quality of life of the person with mental disabilities during the working time of their parents. Parents can leave the children until late (9-10 pm) or also for the whole night if it's needed. It depends on the request of the family. The second goal of the centre is discovering and developing talents of each client: mainly persons with mild intellectual disabilities. After arrival to the centre the clients can have a rest, relax and communicate with friends and professionals. Every day the clients can choose what to do without being forced to follow pre-determinate activities: “one day they can paint, next day they can do theatre or play drama, other days they can attend musical lessons, or do whatever they want - to go shopping, to the parks, to the church, etc.”, - the director says. After that introduction to the centre starts an amazing quick visit of the centre. After that we had a possibility to see a theatre show played by persons attending the centre and operators, see a ceramic laboratory, listen to the centre's orchestra, have a look on some particular painting methods developed in the centre in order to improve the talents of the clients. The visit to “Sviesa” day care centre looked like explosion of productivity. In the quick visit the clients of centre “changed their clothes” to be actors, musicians, artisans, guides. The productivity of “SVIESA” centre seems a strong, effective message to past and actual representation of the people with mental disabilities as unproductive and to be assisted eternally.

## VISITS OF THE SERVICES IN EACH COUNTRY

### CROATIA



During the visit in Croatia of September 2014 we participate in the activities of the day centre provided by Bubamara association. Main aim of the centre is to provide a space where people with mental and physical disabilities can express their desires and needs. People with disability can stay with the staff from 8 am at 9.00 pm. Bubamara day centre hosts about 20-25 person. Within the centre the clients can do different activities such as cooking, having lunch and dinner but also painting, doing handicraft and singing. In this way the day centre give to its clients the opportunity to build social and affective relationships with their peers. The family members are involved as well and specially during the parties and the karaoke activity organized each week the centre is full of people coming from Vinkovci and the surrounding villages. While their sons or daughters with disabilities sing, dance and have fun, parents and siblings can have a rest in one of the spacious room of the centre talking with other members of their community and having fun as well. Bubamara daycentre seems well integrated in the

## VISITS OF THE SERVICES IN EACH COUNTRY

entire local community and organizes important event addressed to the whole community as festivals and concerts.

During the meeting we visited also two other service providers: Mala Teresa e Golubica Association. The first one is a public psychiatric hospital, situated in Vinkovci that hosts 69 persons employing 49 healthcare workers. A special section is addressed to young boys and girl with disabilities not going to school. We visited two of the three floors of the buildings: the one for the persons with severe forms of intellectual disabilities and mental disorders was not accessible for the visits. A net protect the stairs of the building to prevent suicides and the centre is totally fenced in. The visit highlights important issues about the de-institutionalization process actually in progress in Croatia. People with disabilities spent the all day inside the institution separated from the rest of the society. In a rural context with a lack of community based services, Mala Teresa is seen as a “forced” pathway by the families that feel not to be able to take care of their children with disabilities. The 80 percent of this people, in fact, have a families but there aren’t services supporting the family in taking care of the persons with disabilities at home. Recently many psychosocial rehabilitation activities have been included in the program of the institution but they seems not effective in promoting the psychosocial integration of the clients. People in fact are involved in activities like singing or theatre but they aren’t engaged in any kind of activities useful to make connections with the rest of the community. However Mala Teresa is trying build a network of "partners" to support families and reduce the number of its patients. This is complex as the other local care service providers and the families look at Mala Teresa as a not reliable and reclusive institution.

Golubica instead, situated in the centre of Vukovar, is an organization founded by a group of parents of persons with intellectual disability. The association provides a day centre where the persons with intellectual disabilities have the possibility to meet other people and to spend their day, doing a variety of activities such as sports, arts and handicraft. The association provides also a residential service inspired by the independent living model: a supported group apartment where people with disabilities can live outside their families helped by assistants and professionals in daily activities: cooking, washing the clothes, dressing, getting out of the house. The residence hosts about 6- 8 people. The economic resources for building holding the service and for its maintenance have been collected through the donations from the members of the local community.

# VISITS OF THE SERVICES IN EACH COUNTRY

## ITALY



During the meeting in Rome of December 2014 we visited different services for disabilities realized by GAP and by other public or private organizations with which Gap cooperates within the city of Rome. The visit of the services started with a meeting with Anna Maria Palmieri, psychologist and head of the "Service for Disability in the Adult Age" run by the Local Health Agency (ASL). Main aim of the service is to provide assistance to young adult with disabilities out of the school system. Palmieri talked about the difficulty to give an answer to the demand of the families highlighting the risk of a conflict between parents and professionals. The services for disabilities seem in this sense to be requested by the families to reconsider their ends when the school finishes. It emerges the need to change the focus of the services from rehabilitation and therapy to something different. After this meeting we visited the day care centre "Pizzo di Calabria" and the group apartment "The dream of Francesca" that represent two types of services that the persons with disabilities can access after the end of the school. This two services are run by a not for profit organization called Cecilia that started to realize

## VISITS OF THE SERVICES IN EACH COUNTRY

services for disabilities in the 80'. During the visit we met the operators and users of the services. In the day centre and in the group apartment the persons with disabilities, helped by the operators, realize different productive activities such as handicrafts. However this product are usually not sold or exchanged with the local community. Otmar Albertini, the coordinator of the centre, together with the operators explained how this problem has been developed during the time. Activated 30 years ago the social workers employed in day care centre and the group home services followed the philanthropic ideal to realize the integration in the society of the persons with disabilities. Nevertheless the process of integration has revealed to be really hard and the operators nowadays feel to be tired and find difficult to renovate the services in a creative way. After visiting the day centre and the group apartment we moved to the "MadeinPizzuto": the social agriculture project run by Gap in partnership with an association running horse therapy's services for persons with disabilities called "Sagittario". Mauro Benvenuti, president of the organization, explains that himself, his wife and other parents have asked to GAP to be helped in building a productive context to address the problem of social isolation faced by the families of persons with disabilities. A productive context intended as an resource for the future and as alternative to the residential services that has been difficult to attend for their sons and daughters. After a picturesque homemade common lunch furnished in the horse stables and a glass of Sagittario's white wine produced during a social grape harvest, we move to "Locanda dei Girasoli", a restaurant where a group of people with Down syndrome works, to have meeting with the operators and the workers with intellectual disabilities. The social enterprise, started in 2005 by a group of parents of persons with down syndrome, and actually managed by a third sector consortium called Syntesis is trying to become financially sustainable way without public founding. "We're trying to maintain ourselves with the incomes of the restaurant and we are proud of this" the coordinator of the service said. Finally we move from the "Locanda" to the Council of Disability of the VII Municipality of Rome to meet the President of the Council, Rita Gregori. Mother of girl with profound intellectual disability died a few years ago, Gregori, since the establishment of the Council in the 2000, runs on a voluntary basis a service where the families can request information about how to access the services for disability. The meeting with Rita Gregori highlights that self advocacy activities and an active role of the families, in particular of the parents, in promoting the development of the quality of the services represent a resource and a common feature of the context of disabilities in all the countries involved in the project.

## A COMPASS TO APPROACH THE FAMILY SYSTEM

During the YAID project, thanks to the interviews discussion and the visits to the services for disabilities in the partner countries, the project team members identified several recursive problems featuring the relationship between by the families of persons with intellectual disabilities and the services for disabilities. During the project, we identified a set of criteria to address them that we propose here.

The first criterion is to consider the whole family, and not just the persons with disabilities, as the clients of the project and services for disability. This criterion is the product of a critical reflection upon the tendency of the services for disabilities to address the persons with disability in an individualistic way with the aim to cure/reduce the disability. With this criterion we want to stress the idea that the organizations providing services for disabilities have the opportunity to organize services to address the daily problems faced by the whole family instead of trying to reduce/cure the disability.

The second criterion, strictly related to the first, is analyse the requests posed by the family members to the services for disabilities to find out the main problems faced by the different family in their daily life and set up services oriented to them. The requests of the families in this sense are not always clear and in many cases are related to significant emotional problems that risk to remain implicit and not addressed by the services. The interviews show that the problems of the families are specific and related to the way the relationships of the persons with disabilities within the family and within the local context are organized.

The third criterion is to plan and discuss the objectives of the services with the families, the persons with disabilities and others formal or informal stakeholders to project and to monitor the interventions in a shared way. In particular, it is very important to build the continuity of the interventions used by the families from childhood to adulthood to make the services going along the life of the families in a reliable way and to help the families in making plans for the future. This can prevent the development of a distrustful and conflicting relationship among the care service providers, the families and the other agencies providing social services. In this regard the interviews shows that many

# A COMPASS TO APPROACH THE FAMILY SYSTEM

problems are related to the difficulty in defining and going along towards a shared goal and to a lack of coordination

The fourth criterion is to provide moments of fun and conviviality that the family members can experience together with others. In a context where services are usually focused on rehabilitation and therapy, few services are in fact usually addressed to build enjoyable moments within the family or to make the families get in touch with other families and professionals. This can reduce the feeling of social isolation of the families helping them to be more confident in getting in touch with others members of their community. This means also to work to build a frame where family can overcome the embarrassment and the fear of being stigmatized for their problems and where can be easier to ask for an help by professionals if it is needed.

The fifth criterion is to set up useful/productive activities within the project and services for mental disabilities to give the clients the chance to overcome the role of eternally assisted persons starting to carry out an useful social function within their family and community.



## CONCLUSIONS

To conclude this work we would like to propose some of the critical reflections that have led the working group of the project to build the proposed criteria of intervention. We can start saying that interviewing the families, proposing they talk about their problems has been a complex and not taken for granted process. Many parents reported that was one of the first times that someone asked them express their ideas about the services for disabilities and their daily problems since many years. Consequently during the project we asked ourselves why this happens and we recognised that for the organizations providing services, including the partner organizations, can be difficult to ask for critical feedbacks about the services they run. The research highlighted that many families in the partner countries are often unsatisfied of the services. On the other hand the organization providing services seems used to work to give answers to the needs of the families and of the persons with disabilities.

In this regard the interviews shows that in many cases the needs of the families are not clear and that need to be explored and understood. In other terms the ideal to fulfil the needs of the persons with disability often is not enough to realize services effective in addressing the daily problems of the families. During the project we considered this problem as related to the shared expectations of the families and of the care service providers towards the ends of the services. The families and the organization providing services often tend look at the disabilities intended as an illness to be cured. Unfortunately the clients of the services for disabilities face in the most of the cases not reversible chronic conditions. In this sense the cure of the disability represents a sort of illusion promoted by services for the persons with disability oriented to therapy and rehabilitation that do not clearly specify the objectives and the limits of the interventions provided. Reading between the lines of the interviews, this idea is confirmed by the fact that when the persons with disabilities entered the adult age the families start to ask an help to live their daily life in a better way and to make plans for the future. We want here to stress that the interviewed families of young adults with intellectual disabilities, in the very most of the cases, do not ask to the care service providers to cure or rehabilitate the disability. On the contrary the demand posed by the families is to be helped in developing their daily like within and the outside the family.

## CONCLUSIONS

Furthermore the interviews showed that the failure of the expectation to cure, rehabilitate, or eliminate the disability, tend to organize a strong feelings of disillusion and desperation. Feelings that risk to make very difficult the identification of the resources of the persons with disabilities and the construction of projects for the future. On the other hand the building of projects and objectives for the future often represent a frame of confrontation between the families and the care services providers. A confrontation that we have experienced also in the working group of the project made by family members and professionals. In this way we have had the opportunity to reflect more deeply about the relationship between the families and the care service providers. In the interviews we identified, as recursive problem faced by the families, the worry regarding the possibilities for the persons with disabilities to take part in contexts not isolated and somehow protected by the rest of the community. A community seen as too much competitive and unreliable for the weakness attributed to the persons with disabilities. On the contrary we think that the participation of the persons with disabilities in context where to interact with others giving a contribution to the realization of a common product is as key concept for the development of the realized services. In this way we think that can be possible to overturn the idea the persons with disabilities have as their only possibility to live a life as eternally assisted persons. Building the for the young adult with intellectual disabilities the possibility to interact in a productive way with different social context we think it is possible to promote their social integration. Furthermore in this way it is possible to develop the quality of life of the family members who take care of them. To this end an important resource that we identified during the project is to organize moments of socialization, fun and conviviality. The interviewed families say that this kind of services can be important to limit their social isolation building relationships with other families and professionals. What we are arguing here is that the organization of contexts where persons with disabilities and their family members can product something together and have fun represent the alternative to the services aimed to cure and rehabilitate the disability.

Furthermore during the project we identified the lack of coordination of the services and the interventions implemented as a crucial problem. The implementation of services pursuing different ends not integrated between each other risks in fact to increase the displacement faced by the families in facing their problems. The interviewed families in particular ask to be helped in managing the daily problems faced at home. We think that the request to be helped at home, emerging from the interviews in each country, is for the families a way to ask to the care service providers to be closer

# CONCLUSIONS

to their problems and reliable. This represent an interesting challenge for the organizations providing services for disability that poses the issue of training the operators to become competent in understanding the problems faced by the families that are not always explicit and often need creative solution to be treated. In this regard during the project we have understood that if we look to the families as the client of the services it can be possible to recover a source of useful feedbacks. The families' point of view and their active participation in the realization of the service represent in other terms an important resource to develop the quality of the services.

The criteria developed in the project can represent a first step to build new services and interventions flexible and at the same time oriented to the specific problems faced by the families of persons with intellectual disabilities out of the school system.

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For further information visit the web site [www.yaid.eu](http://www.yaid.eu) where you can find a detailed report of the YAID project.



# Lifelong Learning Programme



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