

« Necessary Advancements in Supporting People with Disabilities »



Association for Research and
Training on Integration in Europe

English version

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*Association for Research and Training
on Integration in Europe*

Quality of life
Training
Disability
Equal opportunities
Auto-Determination
Research
Participation
Non-discrimination
Inclusion

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« Necessary Advancements in Supporting People with Disabilities »



NECESSARY ADVANCEMENTS IN SUPPORTING PEOPLE WITH DISABILITIES



Foreword

ARFIE (Association for Research and Training on Integration in Europe) was set up in 1992 as an European NGO to improve the support, the social inclusion and the availability of services to people with disabilities, people with important dependency needs and with associated mental health needs, provision of a quality staff training.

20 years of Existence

Anniversaries are for each organization a great opportunity of assessment of what has been achieved so far and also for planning the activities in the years to come.

ARFIE birth and life represent the EU experience in diversity and integration being a melting pot of different organizations coming from different geopolitical and cultural backgrounds.

The past years, ARFIE has pursued with determination that the EU economic integration shall be accompanied by social inclusion and dissemination of know-how practices. ARFIE has promoted self-determination participation and inclusion of people with disabilities and strongly encouraged innovation and research in service provision.

Through more than 20 years of close collaboration between service providers and training and research centers in the disability field, ARFIE has delivered numerous European projects and publications in disability issues all with the aim to disseminate good practices on how the UN Convention on Rights of Persons with Disabilities could be implemented.

Nevertheless, as an ordinary member of the European Disability Forum, ARFIE has been in close collaboration with organizations and other stakeholders defending the rights of persons with disabilities and promoting inclusion.

ARFIE is not an association of people with disabilities and their families, but an association of service providers and research centers who share the vision that quality training of the staff working with persons with disabilities contribute to the quality of the services provided, increasing the quality of life of the users.

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Initial and ongoing training is a fundamental tool to ensure the quality of services and for this reason ARFIE has promoted research and projects in development of new methodologies and innovative practices such as :

- The first project **“CONTINUA”**, made in the 90s, with the objective of promoting vocational training courses for professionals to encourage the integration between services, families and users.
- Leonardo da Vinci project **“Contiempo”** on training of values and communication, passed on through the innovative method of “Accelerated Learning”.
- **“TRINODD”** Project on dual diagnosis <http://www.trinnodd.eu> that valued the dissemination of former **“TRIADD”** project results <http://www.triadd.lu/>.
- **“COMCADES”** project valuating the training of managers of social economy in various countries in Europe, especially in services for elderly people and people with disabilities.
- **“BENE”** project investigating what safe-guarding means within services provided to people with disabilities.
- **“E-dignities”** project preparing aging of people with intellectual disabilities : analyzing their housing, medical and social - environmental needs.
- **“CQ2-Project”** on active participation of users in the services provided to them.
- **“AGID”** (on-going) project on web based training modules for frontline staff working with aging people with intellectual disabilities <http://agid-project.eu>.

All these projects have been carried out with particular attention to training staff who works with people with disabilities and with the main aim to promote inclusion, non - discrimination and active participation of the user.

NECESSARY ADVANCEMENTS IN SUPPORTING PEOPLE WITH DISABILITIES



ARFIE in the years to come

In today's economic crises where the welfare system and social services are at risk of surviving due to the budget constraints, ARFIE considers that harmonization of the social protection systems throughout Europe could strengthen and contribute to a real EU integration and a SOCIAL EUROPE.

ARFIE believes that a disabled person shall remain the main decision-maker in his/her future life projects and the professionals should remain trained, skilled and qualified to offer an adequate support to the evolving needs of people with disabilities. Moreover ARFIE believes that the social inclusion of people with disabilities enhances the quality of life of all citizens thus fully supports the UN Convention on Rights of Persons with Disabilities and promotes the development of know-how practice for its implementation.

In this publication, service providers will present the current challenges and the necessary developments in supporting people with disabilities such as: developmental disabilities, employment opportunities for the disabled, alternative paths of empowerment, inclusion and active participation of the user at all levels dual diagnosis and mental health issues, as also what EU could do in this field.

Alberto Alberani
Secretary General - ARFIE

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CURRENT CHALLENGES IN DISABILITY : NEW PROGRESSIVE DEVELOPMENTAL DISORDERS



While in France the birth rate of children with intellectual disabilities (primarily Down syndrome) is three times lower than in the 1950s, at the same time, those of children with autism have been multiplied by five times. Children with psychiatric disorders instead amount to nearly 40,000 (increase of 3.2% per year, while the number in psychiatric settings amounts to 1.8 million patients).

The figures have raised serious worries especially since the living situation of the user and his/her family is too complicated and also at edge of exclusion. These disability conditions, despite all the means deployed, do not regress but continuously progress and diversify.

If a real progress has been achieved in supporting children and adults intellectually impaired, poor progress has been done in dealing with autism spectrum disorders and psychiatric diseases.

In these years of fiscal consolidation and austerity on expenses of the destruction of the welfare in the Member States, how could we avoid low quality safeguarding services when supporting persons with disabilities?

The disability generated by a mental illness has been recognized, but there is a constant raise of the number of persons who suffer from it and it is in continuous explosion. Even if the diagnosis can accurately identify autism spectrum disorders, the number is constantly growing.

Facts and Findings

1. There is a **lack of training of the support staff** at least in France and in the French-speaking countries. The support staff working with people with ID is not nor trained or prepared into effectively managing these new pathologies of autism spectrum disorders or of psychiatric nature.

As a consequence, this could mean that the person with a disability will be supported by non-qualified staff and could lead to considering only few types of disability and undermine the possibility of quality care and prevention. However, it is a fact that the support staff is not trained on these issues during the training courses, not even the educators.

CURRENT CHALLENGES IN DISABILITY : NEW PROGRESSIVE DEVELOPMENTAL DISORDERS



The psychologists, which are also too much psychoanalytically oriented, lack knowledge in neuroscience and have serious difficulties supporting persons with pervasive developmental disorders.

2. Research is and remains essential into discovering preventive and curative solutions

The lack of financial resources and the “fungibility” between the medico-social and health system will hinder the research of screening, prevention, vaccination, and even care know-how practices.

Considering these figures, today's and future challenges in the disability field focus on training of the support staff and health care professionals in order to continue to offer effective and quality services to people with ID and in this way fill the gap of the lack of public financing. The devices could be cheaper if articulated by several partners, where each of them contributes to the solution and financing.

Nonetheless, technology has been used rarely up to now and shall be used with greater frequency with the aim to try to offset the lack of the human resources, consequence of fiscal restraints in this field and the fragile economic situation of the families with a disabled person.

ARFIE has already begun to brainstorm and act on how to face these challenges in the most effective way and with this, ARFIE affirms its mission and commitment into researching innovative services, effective training of the support staff as to guarantee integration and social inclusion of this group of EU citizens.

Jean-Pierre Phelippeau
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SAFE-GUARDING WITHIN SERVICES PROVISION TO PEOPLE WITH DISABILITIES



Introduction

The ARFIE network through projects and studies has found that the vulnerability of supported people is the difficulty to express themselves and defend their interests and integrity. Furthermore, it has been revealed that the respect of their rights usually depends directly from the institution and professionals who provide them with services, and rarely from the disabled person him/herself.

For this reason, it is important to give “back” the voice to people with disabilities, their families and professionals who work with them without forgetting that their role is supporting the disabled person into taking decision on their own. Within this study, a unified notion of what safe-guarding actually is has been adopted.

After an extensive literature research it has been accepted the definition of the ANESM considering safe-guarding: “the beliefs which inspire individual actions and collective interactions within a facility or service”. Safe-guarding actually aims to promote the well-being of the users, keeping in mind the risk of abuse and bad treatment”. This is the definition that was used in unified way throughout the study as to guarantee the comparability of the situation in the different EU Member States.

The know-how practices have been considered and compared through an exploratory study and a number of recommendations on training of the support staff have been identified. Nearly 180 people from various cultural backgrounds took part of the survey all of them with the same vision and mission: multiply the conditions favouring the safe-guarding of the user within the services provided.

Methodology and benchmarks

After an exhaustive literature research, it has been decided that the recommendations on the developed good practices shall be based on the benchmarks included within the “Definition and benchmarks for the implementation of the safe-guarding” of ANESM¹.

¹ Agence Nationale de l'Évaluation et de la Qualité des Établissements et Services sociaux et Médico-sociaux

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The following benchmarks have been chosen :

1. The user is co-author of his career and life path
2. Quality relationship between the professional and the user
3. The enrichment of the supporting structures internal and external inputs
4. Supporting the professionals in their approach to safe-guarding

Moreover, safe-guarding which is considered as a key factor into guarantying quality of life of disabled people, has been studied through several components and factors such as : terms of expression, participation, choice and human rights of the users.

Outcomes of the exploratory study

This study has taken into account the different geopolitical /cultural backgrounds which may have influenced, in varying proportions, the answers of the participants.

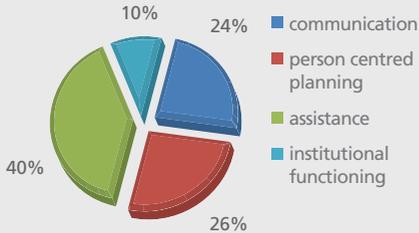
The main factors most strongly associated with the concept of safe-guarding that emerged from the study are the following : **assistance, communication and person centred planning**. The quality of the support /assistance was of primary importance, especially for family members, in terms of professional competence of the team, attention to physical and mental health, sensitivity and empathy of the staff. Instead, for people with intellectual disabilities it seemed to be important to have a life plan custom built with the help of the family and the operators, dynamically adapted to the different stages of development of the disability and supported by active listening. **Active listening** has emerged several times by many of the speakers as primary criteria for treating well /safe-guarding.

Furthermore, the relational and social competence as also trust relationship by the professional care provider, has turned out to be a major importance for the quality of services. Several actors have been individuated as direct interest stakeholders in guarantying good treatment and quality of life of disabled people (supporting staff, health care professionals and families as also policy makers).

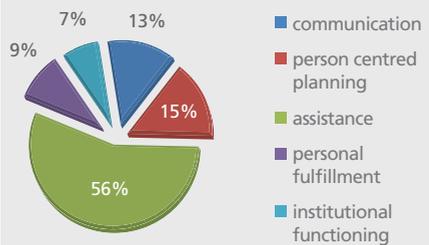
SAFE-GUARDING WITHIN SERVICES PROVISION TO PEOPLE WITH DISABILITIES

Graphic from 1 to 3: Benchmarks representing safe-guarding

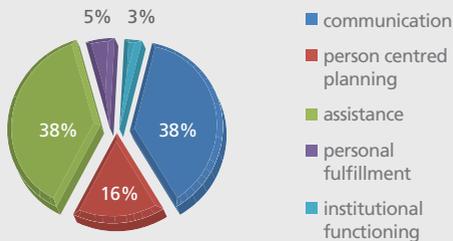
1. Safe-guarding for the users



2. Safe-guarding for the families

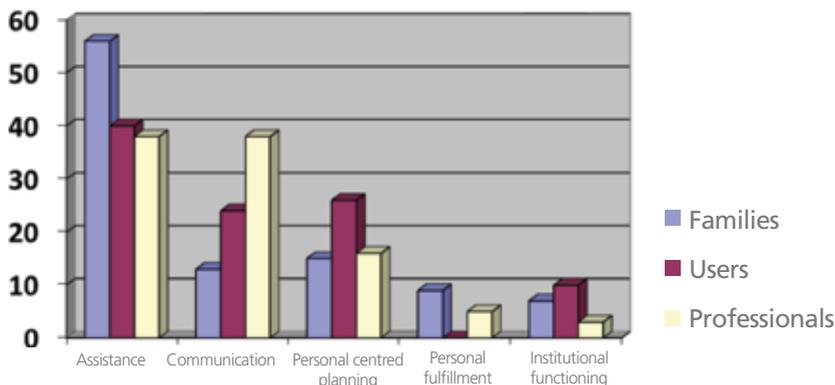


3. Safe-guarding for the professionals



SAFE-GUARDING WITHIN SERVICES PROVISION TO PEOPLE WITH DISABILITIES

Graphic 4 : The different stakeholders and safe-guarding



In a nutshell

“A culture of self-determination and international responsibility”

What has emerged constantly within this study is that safe-guarding is a professional attitude that can be learned by the supporting staff. This professional attitude required to guarantee quality services to people with ID combines both capacities, skills and qualities, respect, empathy as also social networking and communication.

Safe-guarding is a dynamic project since it is never definitive, and the supporting of persons with ID must adapt to the changing expectations, needs, interests, as also to the uniqueness of each of them. The caregiver needs to be continuously trained in order to successfully safe-guard the user and his needs.

The evaluation of the quality of life of the user is a critical measure of safe-guarding since it's difficult to assess. What happiness, well-being satisfaction and quality of life mean for the user is challenging to define since the user himself most of the time it is not independent enough to understand. A good but not definitive and exhaustive definition could be that “quality of life consists of several conditions such as: autonomy in daily life, relationships with others, sexual life, the satisfaction of coaching, physical and psychological well-being, and (the most important) self-determination whether the user is able to.

SAFE-GUARDING WITHIN SERVICES PROVISION TO PEOPLE WITH DISABILITIES



The person central planning has been revealed as the core factor of safe-guarding and also the capacity of **RETHINK** the service providers management code, since the greatness and quality of the services provided is the creation of an opportunity to assess the implementing practices and question them, even when convinced they are good enough.

In a nutshell study and brainstorming on safe-guarding; “bientraitance” is an on-going process since it needs to adapt to the expectations, needs, interests, and uniqueness of the user and all of these variables are subject to continuous evolutionary path.

Christophe Lesuisse

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“PSYCHIC DISABILITY” - A CONCEPT TO BE FURTHER CLARIFIED AND SOLUTIONS TO BE DEVELOPED

The question of psychic disability (*handicap psychique in French*)¹ is not new and in recent years, has been a huge discussion on what shall be considered as priority in the today's disability policy. Yet, terminologies remain unclear and the current responses both in the health and medico-social fields, such as care management, support of the disabled, training of the professionals and rights of the users are little-known. Moreover, sometimes these challenges are inadequately identified or poorly explored due to their complexity.

Notional framework to be simplified

Psychic disability (formerly known in France as “disability caused by a mental illness”) was constructed empirically without any medical or psychopathological evidences.

Still, several characteristics have been identified:

- Psychic disability should not be confused with other psychiatric disorders, since it embodies only one of the features identified by the administrative authorities who recognize the disability.
- Psychic disability is related to a substantial alteration in several areas:
- The impact of the users' thoughts and feelings on the image of him/herself in terms of perception, communication and socialization
- The area of social skills, daily life and autonomy/independence
- The area of social and professional adaptation which restricts the participation in social life
- The area of quality of life in the private and family surroundings
- The area of more or less marked cognitive functioning

Psychic disability thus indicates a persistent heavy and complex situation causing major consequences in terms of autonomy and required healthcare as psychosocial support and long term assistance.

¹ There does not appear to be a strict equivalent in use in English for the French term *handicap psychique* but “psychic disability” refers to a range and an interrelation of impairments, disabilities and handicaps affecting all aspects of an individual daily life, relationships, social functioning and integration that result from lifelong mental health problems.

“PSYCHIC DISABILITY” - A CONCEPT TO BE FURTHER CLARIFIED AND SOLUTIONS TO BE DEVELOPED

If we refer to the international disability classifications, we could say that a number of psychological disorders involve impairments and disabilities, since they generate severely disrupted long term relationships between a person and its environment.

A psychic disability can generate great uncertainty, stigma, loneliness and a strong sense of abandonment -as also chaotic paths which could lead to permanent or long-term cyclical ruptures. As with all other disabilities, it is neither realistic nor desirable to define static mental disabilities. Only a few common features can be identified in psychic disability, since the population is characterized by a great heterogeneity which results in different intensity of personality disorders.

It is necessary to highlight that the collective representations of the mental illness are ambivalent since most of them concentrate on the rights and dignity of life of the disabled without focusing enough on the possibility of being incurable and the marginalization that comes with it.

To have an idea that approximates the quantitative dimension of psychic disability in France, the Psychiatry and Mental Health plan 2005-2008 estimates that between 300000 and 500000 adults have chronic delusional psychosis from which 250000 are schizophrenic.

2. Too simplistic approach

Today is less difficult to accept that a person with intellectual disability is apportioned by psychiatric disorders (depression, aggression, suicidal or addictive behavior...) and becomes widely influenced (positively or negatively) by the family environment, the quality of education, the health care and social support as well as individual factors (personality).

Moreover, the notion of psychic disability puts in question the cure of the same, since the person can be psychically disabled all his life. In addition, certain intellectual impairments or behavior disorders frequently are accompanied by lasting psychic disorders.

“PSYCHIC DISABILITY” - A CONCEPT TO BE FURTHER CLARIFIED AND SOLUTIONS TO BE DEVELOPED

Between these two concepts - intellectual disability and psychic disability - some features may be in common such as the major difficulties in understanding and adapting disorders or severe personality disorders. The difference is that all the above mentioned features do not appear in the same proportions in both cases. We can track “dual diagnosis” or “dual disorder” - intellectual disability with prevailing personality disorders or psychic disability with an evolving deficit in both mental and psychic disability.

The notion used mainly in North America and in some European countries today, takes distance from the traditional classificatory approaches which simplify, adding:

- The consideration of the user in its own singularity and not through a medical or administrative classification (person-centered approach)
- The need to develop a wide palette of solutions institutional or not.

A survey conducted in three regions of France, indicates that between 14% and 21% of the disabled workers in sheltered workshops were previously mentally ill and nearly a third of them has been affected by a psychic disability.

Nevertheless, many innovative solutions have been developed such as: employment training, rehabilitation, housing and socialization- more generally of excellent quality, but unfortunately they have not been effectively disseminated. Here below we present know-how practices that correspond to the plurality of needs and expectations of the mental disabled person.

“Relay Services”(Services Relais): knowing oneself - to do a better choice

Relay services are re-adaptive experiences for mentally disabled. They conduct rehabilitation training and employability activities. According to their legal and institutional framework, these services represent a fairly unique example of participation of the medico-social sector in social and professional rehabilitation of psychic disabled persons.

The proliferation of this type of support services is organized around targeted objectives and is desirable since:

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1. There is insufficient diversification of support within the mental health sectors. Alternatives to hospitalization are few even if, in the last thirty years, the majority of psychiatric beds have been removed. Preparation for re-integration and developing a social life for the user is almost non-existent in the field of mental health.
2. There is a persistent partitioning between health and social issues. The directives regulating mental health support actions refer to the strict interaction with the social sector associations, even if in practice very few agreements have been signed and developed between the associations and the psychiatric sector. Instead of establishing agreements with the associations (which are not always in favor of this collaboration), psychiatric sectors rely on the ambivalent recipient and institutional system (in France it has been established by law on February 11th 2005). The definition of complementarities between the mental health and the social sector remains infrequent. This generates the exclusive use of para-hospital services or orientation towards sustainable but unjustified sheltered workshops.

The Relais services should be developed to react with flexibility to the personal and psychiatric evolution of the user. Several factors have contributed to their development such as:

- Many psychiatric patients demand to work in sheltered employment
- The demand of the placement services to accept and place within their services users with mental illness, even if they have very poor social skills

To develop links with the social environment-access to services offered by the community and the acquisition of restoration skills a (re)internalization of the social rules and their implementation - an active participation of the user is necessary. The support services for each user and the Relais services within a general framework (rotation between the workplaces services, the time of enrollment, learning social and psychological support), will help and encourage each individual to develop a personal project such a job and an autonomous housing arrangement.

Training and ongoing evaluation tools throughout the stay, capabilities, weaknesses, motivations and potentials included within the Relais services allow the different stakeholders (mental health teams, placement services and patients)

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to meet regularly (every two months) and jointly select a route without being prisoners of what has been before the avulsion (sometimes it requires up to 10-15 years).

The way Relais and other support services operate, demonstrates the importance of creating flexible responses/reactions in order to allow to the user to create a personalized life path which is not a forced placement. Social integration becomes an individual choice and it became more likely to be sustainable.

Modulated employment services (SEM): tailor-made sheltered employment

Creating specific integrated entities within the sheltered workshops with the aim of matching specific needs of the user could be an appropriate response to the users' rights and needs.

An example is the so called Relais services such as: the establishment of suitable jobs for psychically disabled characterized mainly with unsociable behavior.

The support of the disabled worker is very individual. The presence of a constant or intermittent educator is needed within the development of the workstations including professional practice. Working time is defined regularly and adapts to the health and professional skills of the disabled worker.

These arrangements are a co-decision between the disabled worker, the management team of the host structure and the mental health sector. If considered necessary other partners involved in the social support of the disabled are regularly assessed, in order to achieve a better adaptation facilities and to address users' needs in the most efficient way.

EPI services (jobs for insertion) address a supported and assisted integration in ordinary jobs

The EPI services which address an “accompanied and assisted” integration have been created with the aim of better professional integration of the disabled worker with psychic disorder. Within these services the workers have a status of an employee according to the labor law. The user benefits psychosocial care provided by the workshop team at the moment when he becomes an employee of the association who offer **supported and assisted integration**.

But very often these activities are difficult to develop due to the lack of financing even if they represent an excellent tool for transition of the disabled user from

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sheltered workshops to ordinary labor market. Moreover, it's still difficult to sensitize public authorities with the many problems which arise in obtaining financial help for an appropriate inclusion of the disabled. For this reason it becomes less difficult to manage a classic institution instead of developing new paths and services essential to the implementation of flexible solutions tailored to the mentally disabled user.

In a nutshell

Innovative health and social services need to be developed and supported by public financing in order to offer a quality support service for the disabled such as: work, education, housing and efficient training programs for the professionals working with them.

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INCLUSION IN THE LABOR MARKET OF PEOPLE WITH ID AND LEARNING DIFFICULTIES - NEW EMPLOYMENT OPPORTUNITIES

Introduction

51 million of the 495 million EU citizens, aged between 16 and 64 years, are people with disabilities or are long-term disabled. This is nearly 10% of the whole EU population, and within them, between 15% and 50% is unemployed. Unemployment of disabled people is two times more in comparison with not disabled people (ex. Germany: 14.5% disabled against 7.7% non-disabled). The number of unemployed people with disabilities varies between the Member States within the EU. Also it is worth mentioning that there is a lack of clear statistics within each country of the number of unemployed disabled. Moreover, the data between the Member States is not easily comparable since the definition of a disabled person is not unified and it varies according to the legislation in force and administrative standards.

The vast majority of EU Member States have an employment provision policy for disabled people but these measures are not of binding nature as they take the form of recommendations and most of the times no sanctions are foreseen within national legislations if the enterprises do not comply with them. Therefore, there is non-compliance on the employment rate of people with disabilities by the enterprises in most of the countries, as also employers do prefer to pay the penalty/fine rather than adopt these recommendations/directives. Studies show that these employment policies for disabled people actually serve only to delay the unemployment (a big focus on problem management instead of problem solution). The problem is that after a period of unemployment, the chances of a disabled person to go back on the labor ladder diminish even more.

The UN Convention on Rights of Persons with Disabilities (UN CRPD) represents a significant change since it guarantees the right to work to the disabled and has awakened a great debate on the EU and on a national level emphasizing the need of spreading the special facilities such as sheltered workshops and other alternative forms of employment.

With regard to the integration of the disabled within the labor, we currently face the so called "flexicurity" problem: meaning to show the complicated link between social security and social insurance. Many (including disabled)

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people opt for benefits instead for “employee” statutes since they consider the integration of the disabled people within the labor market of high risk, even if being integrated within the labor market actually implements citizenship rights to disabled people and make them feel equal citizens.

In Germany most of the disabled people are employed in the mainstream free labor market (eg 1070000). Another significant alternative offering special working conditions to people with disabilities, are the so called sheltered workshops (In Europe there are about 550000 employees inside the sheltered workshops and in Germany: 297000).

This employment policy especially focuses on people with intellectual disabilities, with learning disability and severe mental impairments. However, everywhere in Europe, including the newly admitted Member States, there is a tendency of growing alternative employment opportunities and solutions to the sheltered workshops. In particular, supported employment policies with job coaches within the free labor market are conducted by enterprises and cooperatives. Instead the public employment companies instead integrate disabled people as clients in their employment businesses.

All these alternative employment solutions (in Germany with approximately 67000 employment and jobs) are estimated to have employed about 150000 people across Europe. Despite all of these successful stories, there is still so much to be done since the rate of unemployed disabled people persists really high (eg Germany 160000 or approximately 15%).

Considering the active labor market policies for disabled people instead, it is a great disappointment knowing that there are no accurate figures and impact assessment studies on the inclusion measures and policies. These studies are still unable to reveal exactly what impact the labor market inclusion instruments and measures had: such as wage subsidies for the enterprises, the cost of workplace equipment, the success through job coaching and supported employment etc.

However, the studies reveal that the motivations of the employee/worker and his competences are crucial into being integrated in the free labor market. Still, a major problem remains the poor vocational training for people with disabilities

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and their transition from school to work. The school system and the labor market are not well linked and there is no competences development needed for the labor market, foreseen within the school curriculum. Likewise, the studies demonstrate that counseling and job placement needs to be developed in cooperation with the enterprises.

Nonetheless one thing is sure ; the integration services and other social enterprises will increasingly gain an important role into employing people with disabilities.

New paths to employment of people with disabilities

Offer of variety of employment opportunities instead of inclusion at all costs, shall be a MUST

Innovation within and outside the sheltered workshops

In Germany, approximately 300,000 people with disabilities are employed within sheltered workshops. It is estimated that about 10% of them no longer work in these traditional workshop trades, but within the free market and business oriented enterprises.

Nevertheless, only 3% of those working within the sheltered workshop stay there and never change their job. The organization goal of this sheltered workshop preparing the transition from sheltered employment to open labor market, has been largely lost in Europe.

For this reason we need to develop new employment opportunities for disabled people by collaborating with established private enterprises, where the disabled becomes an employee under help and supervision of job coaches/assistants. These new employment possibilities are already subject of vocational training activities and study in cooperation with established private companies and enterprises.

INCLUSION IN THE LABOR MARKET OF PEOPLE WITH ID AND LEARNING DIFFICULTIES - NEW EMPLOYMENT OPPORTUNITIES

Public employment associations and social enterprises

In Germany, it is estimated that about 20,000 people with disabilities are working in employment and social enterprise companies. These companies are not profit-oriented and not market-oriented if compared within normal business oriented enterprises. They have an educational, social or an employment contract, which derives from the respective laws of the countries concerning non-profit organizations. Employment there is usually only temporary, wages are not very high and are often only a compensation for the additional costs of the employee such as: work clothes, travel costs, etc.

The non-profit-oriented employment enterprises suffer greatly of the pre-management process to be developed with this specific target group of disabled people (otherwise long term unemployed) and manage to cope well enough to satisfy their expectations. Moreover, they are normally considered in the same way as the long-term unemployed non-disabled people who do not always appreciate this.

Integration firms and cooperatives

In Germany, enterprises with integration goals and cooperatives offer nearly 10,000 jobs.

These companies operate directly on the free market and are subsidized by the so-called under-performance compensation of their disabled employees. These subsidies, however, are not enough to compensate the additional costs of care for the disabled and for the lack of service delivery. Furthermore, these companies suffer from the lack of business consulting, networking and capital. Thanks to the long term claims and demands on the above mentioned issues, social enterprises have obtained loans with advantages and the EU has adopted a separate (more favorable) legislation with regards on the financing of these social enterprises with integration goals and missions.

INCLUSION IN THE LABOR MARKET OF PEOPLE WITH ID AND LEARNING DIFFICULTIES - NEW EMPLOYMENT OPPORTUNITIES

Supported Employment

Supported employment is targeting disabled people with an employment potential in the free market. Most of those who work in support employment are with learning disabilities and other special needs school graduates. The supported employment within the enterprises is conducted by the so called-job coach and they are locally supported. Some come without an external support because the job coach attends special concerns of people with disabilities. Up to today, this alternative form of employment hasn't been sufficiently developed, unlike in the U.S. where it has been introduced for more than 30 years. Likewise the main focuses of this measure are mainly people with learning disabilities and mental handicap. It is sad to observe that the "supported employment" is not promoted enough as an alternative by the lobby of the sheltered workshops and disability policies. Therefore, this alternative is not considered as a priority from financial point of view compared with the financial support and subsidies that sheltered workshops enjoy.

In a nutshell

The existing financial support that sheltered workshops receive shall be diversified and available to all alternative forms of employment for disabled people. So far the supported employment received only 10% to 30% in comparison with the sheltered workshops funding. The administrative procedures of these new forms of working arrangements for disabled people in Europe needs to be further promoted, developed and simplified. For this reason, the EU through the European Social Fund should stress Member States into conducting a policy of employment and inclusion for all in order to guarantee a full implementation of the UN CRPD within its Member States countries.

Rainer Dolle
Arbeit und Bildung - Germany



For almost thirty years we deal with people with intellectual disabilities and serious dependence needs. Many of them today have become adults and for this reason we need to deliver services adequate to their needs and rights. This is the pioneer generation of aging people with intellectual disabilities who become older and forces us to reflect on issues never faced before. Since the quality of aging and services relies in the first place on personal, cultural, economic and environmental resources available to the aging person with ID, it is clear that the aging of a non-disabled person will develop very differently from the one with congenital disability. Nevertheless, it is necessary to mention that sometimes there is an overlap between the aging of a disabled and non-disabled person, due to a pathological aging and the consequences that it comes with.

There is no “threshold of old age” an age that defines exactly when a person becomes older-unanimously accepted. The World Health Organization recommends that the sixth decade of life of the person with ID to be considered as a chronological age. But the progressive loss of skills and cognitive impairment can occur even earlier either for specific pathological conditions either when the social welfare support is not adequate. If 65 years old is considered as a threshold of conventional aging, when talking about aging of people with ID the threshold considered is between 40 (for Down syndrome) and 50 years old. Some studies have shown that the severity of mental retardation can affect life expectancy: 74 years for mild mental retardation, 67.6 years for moderate, 58.6 years very serious mental impairment.

There is also an “administrative” threshold of old age that needs to be considered. It is the age when the person can enjoy the incentives for cultural goods and transport, or for access to a network of health and social services. In Italy, a non-disabled aging person is entitled to benefits after its 60th year and after 65th, the person is entitled to benefit all the dedicated service to the aging population. A person with ID instead is entitled to benefits for all his/her life since he/she is a disabled person. Moreover the person with ID rarely retires since is rarely employed and enjoys an access to the service network for disabled up to 55 years. Once 55 years old, the disabled can enjoy the grid of serves for elderly people.



In this way the aging disabled person gets out of the service network for disabled who focus more on pedagogic-enabler aspects and uses the services dedicated to elderly people more concentrated on health and care. The strengths and weaknesses of these two approaches are briefly presented in the following table :

Psycho-pedagogical approach for disabled	Geriatric approach for elderly people
Strength	
Person centered approach and life path projects	Use of scientific methodology
Use of the relationship as a tool	Multidimensional evaluation and global approach
Weaknesses	
Scientific weakness of the Psycho-pedagogical approach	No personalized approach - excessive standardization of the intervention and care
Reduced use of the evaluation tools and lack of attention to a multidimensional approach	Risk of medicalization of the care
No global approach	Reduced attention to the relationships and social environment

(source : Renzo Bagarolo, I luoghi della cura, 3;2005: 6-8)

If we say that the residential services for older people are often unprepared and inadequate to accommodate elderly people with disabilities (generally younger than the rest of the residents) and that the geriatric approach may not always be sufficient to deal with the problems of the disabled with ID, it is also true that many services providers for people with ID respond inadequately to the aging of people with ID since they are not providing services that match their needs and rights.

Aging is not a disease, but a process that includes losses and gains. An efficient evaluation of the pathological conditions and its distinction from the normal



physiological effects of aging needs to be conducted in order to prepare the user to face better this transition. The aging of the disabled with ID, however, is almost never considered as a process that can be slowed down, modified or actively experienced, but most often as the result of a worsening of the syndrome that has produced the disability.

The American Association on Intellectual and Developmental Disabilities (AAIDD) and numerous international experts (including Christine Bigby, Nancy S. Jokinen, Anne O’Rourke and co-workers) point out that in addition to the typical needs of the aging population (appropriate opportunities for retirement, support for the grieving and the loss of family members and caregivers, maintaining social networks, quality care for health maintenance, residential adequate arrangements) aging people with ID have more specific needs due to the higher prevalence of sensory and motor impairment, the higher risk of developing dementia, the increased prevalence of psychiatric syndromes and symptoms (depression, anxiety and delirium) and the lower socioeconomic background which involves an increased health problem risk.

The professionals working with people with ID must be able to detect at an early stage all the related changes of the new and often more complex needs of the person with ID, in order to offer to the user the best possible quality of life in line with his/her interests, lifestyles and residual capacities. Supporting people with ID must be accompanied by activities that protect their right to social inclusion since much more than others people with ID are at risk of isolation and exclusion.

A new different approach in training professional and front-line staff working with people with ID is necessary such as: provision and acquisition of new skills, building a common language and a continuous dissemination of know-how between the different professionals. The training programs should include the different aspects that affect the lives of older people with ID: health and nursing, psychological, relational, nutritional, and social needs. Legal protection of people with ID is challenging today since most of them not capable of self-determination and destined, in most cases, to be represented by a family member.

It is also important to provide courses and training which could help the operators to overcome the difficulties (especially emotional/relational, but also operational) related to the aging of their users, in order to facilitate a more competent and responsible takeover.



Know-how of the training and upgraded skills shall be widely disseminated since they permit structured opportunities for discussion between the operators, all with the aim to develop efficient solutions that could match the rights and needs of people with ID.

ARFIE has been a promoter of several European projects focusing on aging persons with ID with the aim to study and exchange good practices between different EU countries on the evolving needs of aging people with ID (within the e- dignities project the countries involved were: Austria, Belgium, France, Great Britain, Portugal and Italy).

The purpose of the project was to find new effective strategies that could ensure the highest “quality of life” as possible for the disabled as they get older, investigating all areas of intervention: thought exchange know-how practices and developing innovative facilities within the services provision to disabled people. Assuming that the Quality of Life is a universal concept including an integrated vision of the biological, psychological, cultural, economic and social well-being of the user, recommendation on the EU level has been identified in the following fields:

- Health-related issues
- Housing arrangements
- Employment opportunities
- Social environment

With main focus on:

- User involvement
- Development Services
- Training of support staff
- Social Cohesion



The questions that have often risen were mainly focused on if there are many differences between aging with disabilities and aging of non-disabled. What emerged very clearly is the need to involve users as active citizens and that a lot of opportunities need to be guaranteed to persons with disabilities, even in the most advanced stage of life.

Active involvement of user/person with ID means: considering his/her will; ensuring to the user the freedom of his/her choices, supporting him/her in decision-making by providing the user with adequate time and space and active listening.

Moreover, it remains essential to allow things to go in a different way rather than how the staff had planned as to really represent the user's will and needs.

An adequate approach shall address autonomy, respect, dignity and freedom of choice as core values when supporting people with ID since it represents an approach where the solutions are not imposed but are designed and built together with the user who stays the main actor and decision-maker of his/her life path.

Lara Furiere & Marie Christine Melon
Cooperativa social CADIAI Bologna - Italy

AGING OF PERSONS WITH INTELLECTUAL DISABILITIES : A MAJOR CONCERN IN THE YEARS TO COME

Life expectancy of the EU population is steadily increasing and people with disabilities are no exception to this rule.

In a period of fiscal consolidation within the EU, how to provide quality of support services as well as solutions to needs and expectations of aging people with disabilities has become a major challenge.

Since services need to meet the needs of aging people with disabilities the question is: how to approach each situation by providing a coherent and proactive framework ?

The expression of the people's desire

The best way to “get it right” when providing services, is to match an adequate supply of services which meet the expectation and demands of the user. However, this is not always the case since the social policies implemented in the different countries and their quality depend on the financial resources allocated for this purpose. Therefore, we need to do a compromise between the desires and feasibility from an economic point of view, taking as much as possible into account the client's life project and its adaptation to the environmental circumstances. Empowerment of the person with disability and his/her participatory approach shall be promoted in all circumstances by the service provider regardless of the nature and the degree of disability.

Needs assessment

As for everyone else, the individual needs of persons with disabilities are transversely spotted around medical care needs which increase with the aging of the person. However, the evolution of the different clinical profiles has also lead to take into account the environmental and relational factors as to achieve life balance. It becomes necessary here to mention the loss of autonomy and the dependence of the person, when considering what quality services do actually mean.

This population of aging persons with intellectual disabilities considered also a “pioneer” generation should not undergo a process of more dependence and more “handicapping”. **It shall be avoided that this double difficulty (disability and age) adds double obstacles such as social and professional**

AGING OF PERSONS WITH INTELLECTUAL DISABILITIES : A MAJOR CONCERN IN THE YEARS TO COME

“disability”. For this reason, the aging of people with intellectual disabilities represents today a major challenge within the services provided since finding appropriate solutions that will soften the sudden changes in their lifestyle and avoid any exclusions is needed.

Therefore policy makers shall seek to provide a flexibility framework able to manage and arrange the different passages, instead of proposing solutions relying on household disruptions.

How to efficiently reply to a multifactorial panel of needs of an aging person with ID through resource planning combined with other necessary devices ?

Public policy

- Even if comparative studies reveal a great heterogeneity of the care systems in Europe, several converging trends can be observed :
- The trend to favor home support as long as possible (seen the percentage of public expenditure in this direction)
- Increased attention to the family caregivers
- Development of financial benefits mechanisms to encourage the choice of the user
- The competition between care services and support services...

European public policies tend to support the aging person with disability in different ways such as:

- The Malaga Ministerial Declaration (7 & 8 May 2003)
- The Graz Declaration (June 2006)
- The Declaration of St. Petersburg which has launched Persons with Disabilities Action Plan 2006-2015. Among the five transverse axes of the European Action Plan, aging of people with disability takes primary attention.

AGING OF PERSONS WITH INTELLECTUAL DISABILITIES : A MAJOR CONCERN IN THE YEARS TO COME

This community legal framework has been globally strengthened by the ratification of the Convention on the Rights of Persons with Disabilities in New York December 13, 2006.

On national level

The Council of Europe has issued on July 10th 2009, a Recommendation to its 47 Member States on aging and disability in the XXI century. According to the Committee of Ministers: "The desire of aging persons with disabilities and elderly with disabilities to live their lives with the greatest degree of freedom and autonomy possible in the human and physical environment, shall be facilitated by the services".

The family instead plays an important role in the majority of countries. In Italy, it was the family who has coordinated the interventions at home, while this role in other EU countries such as Germany, Denmark, UK and Sweden is the so-called care manager.

Finally, there are also increasingly diversified living areas, ranging from home to medical establishment: private habitats within a community where the advantage is the maintenance of a social life.

E-learning and training of support staff working with aging people with ID.

The solutions within and out of the institutional framework-viewed as a diverse range of services and multidisciplinary management of people within their environment-need to be adopted to the interaction of the services.

ARFIE (Association for Research and Training on Integration in Europe) in the last fifteen years has considered the provision of services to aging people with ID, as one of the major challenges to be faced. Therefore, ARFIE held several studies and seminars to solicit innovative solutions in services provision that could match aging people with ID needs and expectations. The European partnership's aim is to address the needs of aging persons with ID by providing training and support to the staff and caregivers working with the users, contributing to the users' quality of life.

AGING OF PERSONS WITH INTELLECTUAL DISABILITIES : A MAJOR CONCERN IN THE YEARS TO COME

Filling the gap between research and services provision on this issue has been considered as a core objective. The pedagogical innovation to address social workers and health professionals geographically dispersed, has highlighted the need of accessibility and challenged the conventional thinking that the face to face is the most effective way of transmission of knowledge. Nonetheless, many adaptations have been necessary within the different training modules, but a wide coherence has emerged without having a negative impact at the quality and developments of the products.

Beyond the general knowledge in gerontology, the training of professionals on how to offer services maintaining links with the environmental management and prevention has emerged as of fundamental relevance.

Six modules and topics have been chosen as a part of the e-learning platform of the AGID project :

- Aging Processes of People with ID
- Pathological Aging in People with ID
- Person Centered Planning
- Care Management - Organization of supporting of aging people with ID
- Social Network and Communication
- Emotional Regulation for Professional Carers

These modules have been articulated around the somatic and psychological processes of aging as to achieve successful training of the staff, thus quality service provision when supporting aging people with ID within their life projects and environment.

Patrice Morel
Les Genêts d'Or - France

A NEW TRAINING TO IMPROVE EMOTIONAL REGULATION SKILLS FOR PROFESSIONAL CARERS WORKING WITH OLDER PEOPLE WITH ID

Case Vignette

For the last four years Mr. W. has worked as a front-line carer in an assisted living community for older people with an intellectual disability (ID). Mr. W. was always very proud of the fact that individual care was not an empty promise, but taken very serious at his place of work. People's wishes were taken into account and the daily routines were handled as individually as possible. This created more work for Mr. W. and his team, but they were happy to go the extra mile.

Lately he was confronted with several difficult situations at work: Mrs. M., a resident in the assisted living facility displayed difficult behavior during the past few weeks. She was aggressive and violent towards other residents and Mr. W. The team and residents were also confronted with the sudden and unexpected death of Mr. F., another resident. Lastly a team-internal problem arose as one staff member had to often swap shifts at the last minute due to a family member in need of care.

As much as Mr. W. tries to meet everybody's needs, he has started to notice that it is getting too much for him to handle. He has realized that his contact with the residents is not as personal as it used to be and he has a feeling of reluctance when he has to go to work.

Why is training on emotional regulation relevant for professional carers working with older people with ID ?

Studies on stress and strains in professional carers revealed that 25% respectively 32.5% of front-line staff working with people with ID were confronted with intense levels of stress. Furthermore, specific challenges suggest that professional carers working with aging people with ID are confronted with a high amount of possible stressors.

Stress levels of professional carers in general are influenced by challenging behavior. However, the likelihood of challenging behavior increases in older persons with ID, as there is a higher risk of dementia and other age associated diseases. Furthermore, the additional time needed to care for aging people with ID due to their lowering level of daily competence also directly influences the perceived stress level of carers.

A NEW TRAINING TO IMPROVE EMOTIONAL REGULATION SKILLS FOR PROFESSIONAL CARERS WORKING WITH OLDER PEOPLE WITH ID

Additionally, higher age of the persons with ID increases the probability of emotional challenging life events, such as social changes like retirement and the loss of relatives (especially parents) or dear front-line staff.

Consequently, a variety of different stress factors can contribute to stress in professional carers working with older people with ID. On the one hand, these factors include the characteristics of service users, as mentioned before. On the other hand, within-staff factors, like younger age of the professional carer, a lack of knowledge about challenging behavior or a deficit in strategies dealing with stress can also increase the perceived level of stress.

It is thus not surprising that several studies show that the way in which work related emotions are handled by professional carers has great impact on how likely they perceive high levels of stress.

In accordance to these findings and to provide professional carers with a broad set of skills to increase their ability to regulate emotions, the University of Vienna developed a training module on emotional regulation skills in the context of the AGID project.

What are the objectives of the training ?

The module's aim is to give front-line staff caring for people with ID the possibility to better cope with stress and challenges in their everyday work life.

The content of the module aims to help during times of extreme stress and pressure by reducing negative effects caused by stress, maintaining a high quality of life and ensuring a socially responsible behavior towards people with ID and colleagues.

What is the content of the training ?

The training is subdivided into three main topics. The first chapter provides a detailed overview of emotional regulation and specific stress factors challenged with when working with aging people with ID. Based on case vignettes and exercises, professional carers will receive insights into the following topics :

- What is emotional regulation ?
- Stress factors in your work environment.

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- Stress factors when caring for aging people with ID.
- Specific aspects when caring for people with ID.

The second chapter addresses consequences of stress and pressure as well as preventive coping strategies. Specifically the following issues are covered :

- Stress and burn out.
- Aggression and violence.
- Benefitting from resources in the care environment.
- Co-workers.
- Problem solving behavior.
- Relaxation techniques.

The third chapter provides an overview of specific strategies designed to help with challenging situations when caring for aging people with ID. In several exercise courses participants acquire skills and competences in :

- Central life events of aging people with ID.
- Communication skills - how to deliver bad news to people with ID.
- Death and grief when caring for people with ID.

The module is concluded by a summary of the most important issues. Also, a self-test at the end gives professional carers the possibility of testing their knowledge they have acquired in the course of this module.

Which competencies can be acquired ?

Professional careers should have acquired the following competencies after completing the module :

A NEW TRAINING TO IMPROVE EMOTIONAL REGULATION SKILLS FOR PROFESSIONAL CARERS WORKING WITH OLDER PEOPLE WITH ID

- Ability to reflect and systematically explore stress factors in one's own work environment.
- Recognition of one's own risk of a burn out.
- The ability to recognize and handle organizational or personal violence and aggression.
- The ability to systematically recognize and benefit from resources available in the work environment.
- Measures to ensure a social and productive exchange in a professional environment.
- Knowledge of goal oriented problem solving strategies.
- The ability to exercise relaxation techniques.
- Reflecting on one's own understanding of aging and death.
- Communication skills when delivering bad news.
- Knowledge of important steps in case of the death of an aging persons with ID.

More information/Contact

If you are interested in the module or need further information, please contact the project team at the University of Vienna (andreas.kocman@univie.ac.at).

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THE CONCEPT OF INCLUSIONS AND ITS (DIFFICULT) IMPLEMENTATION



“I cannot say whether it will be better if it will change; but what I can say is, that it has to change in order to be good “

Georg Christoph Lichtenberg (1742-1799)

It would certainly be interesting to do a little background of the concepts used through history when talking about taking care and supporting people with disabilities :

- Exclusion
- Protectionism (in asylums type structures)
- The concept of normalization
- The concept of integration
- The concept of inclusion

The concept of inclusion has taken a major importance when the UN Convention on the Rights of Persons with Disabilities has been ratified in most of the European countries ! Here’s a reminder of the article concerned :

Article 19 - Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that :

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement ;**
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community ;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

THE CONCEPT OF INCLUSIONS AND ITS (DIFFICULT) IMPLEMENTATION



Currently we can observe two types of discussion on what inclusion should be :

- There is a **theoretical approach** that embraces ideological, political and social concepts which sometimes seem even visionary.
- And an **institutional approach** that often makes reference to the daily support of people with disabilities and know-how by the professionals working with them.

The ideological approach of inclusion

The inclusion sought, desired and claimed under this approach requires the establishment of a social policy, social work, and a policy protecting groups at risk of marginalization which ideally shall answer the following challenges :

How to legally ensure/provide the establishment of services and financing methods :

- a) That in the first place highlight the disabled's needs instead of the financing needs and interests of the services ?
- b) That prevails the disabled people's will over the hyper-protectionist attitude ?
- c) That focuses on the disabled people's skills /abilities rather than their disabilities ?
- d) That focuses more on a territorial approach (Sozialraumorientierung) as a priority (compared to a targeted intervention on minority group) ?
- e) That does not focus the intervention on the support of a targeted minority, but would be rather based on inclusive initiatives ?

The institutional discussion on inclusion

It is not needed to enter in in-depth discussions on this approach since the arguments opposed to the "ideological" approach are well-known. Even if this approach is rooted in the everyday's work of the service providers, still a critical analysis and a hindsight perspective need to be presented.

THE CONCEPT OF INCLUSIONS AND ITS (DIFFICULT) IMPLEMENTATION



Just as a reminder, here some remarks we still often hear :

- *People with disabilities remain understood as people who need support since it is considered that they could not bear the consequences when confronted with the society. Their limits are highlighted and if pushed too far it might result in more marginalization and exclusion.*
- *This approach favors the disabled with a certain autonomy and creates new disabled and excluded minorities within the same population of disabled persons.*
- *The people with intellectual disabilities need to be included in a secure and separate frame (often desired by the parents !).*

Actually we must not choose between the two approaches since it is only a matter of time they will become closer one to the other. This could be seen if we observe and compare the discussion between the two approaches in the last 20-30 years and today's outcomes (ex: housing support within a community, participatory approach of the user within the services provided to him/her, etc.).

Certain values and beliefs need to be identified:

Today there is a more logical and historical opening in sense of inclusion. We can trace it in history when a social or socio-educational approach in supporting people with disabilities has been adopted. A regressive return would mean going back to the medical approach which focuses on the disabilities instead on the abilities of the disabled person and that would bring negative consequences !

Not everything can be done at the same time in the same place since it is a long process and the entrenched habits and beliefs are a big challenge to be faced. As with any paradigm shift, the changes must follow, in different phases. But still several possible paths and approaches remain available.

Equity will not of course be achieved in one day since it is a long and challenging aim to be achieved !

On the issue, the EU instead has adopted an open-minded approach since it has favored the dissemination of different know-how practices developed in different geographical and cultural contexts, and in retrospective, a common trend towards greater inclusion can be noticed.

THE CONCEPT OF INCLUSIONS AND ITS (DIFFICULT) IMPLEMENTATION



Some essential elements :

The debate on the inclusion is closely related to other topics and concepts difficult to be approach separately :

- The participation of the disabled person at various levels :

An inclusive approach must be coupled with a participatory approach. The person must be directly involved in issues that concern him/her such as: the implementation of the project life path, his/her professional life development, the preparation of his/her aging (various tools are used in this approach : person centered planning - *persönliche Zukunftsplanung* - personal life path planning, etc.)

We can identify on this issue many examples in various countries as also initiated projects by ARFIE (Mediander, CADIAI, Fenacerci and Lebenshilfe Austria, for example). An example of participation and self-representation of the disabled is their participation within the Board of Directors of the service providers, etc. The principle of participation and representation must be the same for the other stakeholders involved in the coaching process: families, friends, professionals, etc.

- Respect and implementation of the rights of persons with disabilities

The legal framework must be adapted and prepare the disabled to legally make decisions or be supported to make one (supported decision making). Thus, remains essential the recognition of the legal capacity of the disabled person and as well as the development of support in his/hers daily opportunities, which could make them understand and choose. To make this feasible the assistant/career is trained not to decide instead of the disabled, but to mediate with the environment-network of friends and trusted people by the disabled, and assist the disabled in taking a decision on his/her own. This approach does not hinder or limit the legal capacity of the disabled.

Equity must be “highlighted” and supported by law! The English-speaking countries are one step ahead (even if in some countries, like Ireland, the discussions are still problematic and on-going) in terms of legal capacity. Sweden

THE CONCEPT OF INCLUSIONS AND ITS (DIFFICULT) IMPLEMENTATION



and Germany, for example, have revised their legal framework to make it more flexible and adequate to the different situations of self-representation and advocacy. Nevertheless, when safe-guarding and supporting people with disabilities is the concern, France also made progress in adopting more adequate legal framework.

- Decentralization and deinstitutionalization of the services (community based services and leaving - Sozialraumorientierung)

Deinstitutionalization of the services is an issue of great discussion in Austria, Germany and Eastern Europe, as a focal point of social work. (Sozialraumorientierung)

Deinstitutionalization also remains a focal point when we talk about achieving inclusion of marginalized groups like people with ID. Recognizing direct interaction with society and the environment as fundamental means recognizing equal citizenship rights of the disabled people (this allows a different perspective on disability, where the role and the status of the disabled people change and allow self-esteem). Citizenship rights can be implemented and experienced only in a social context and environment.

- The provision of means

The disability policy in the Member States needs to ensure the provision of adequate resources, either through personal budgets or supporting allowances (socio-educational) in line with the needs and rights of the disabled person.

When we talk about moving **towards more inclusion, which shall lead to changes at various levels and within various structures and services**, we must consider :

- Change in the supporting measures: person-centered, measures to promote the training of users and professionals with a focus on both stakeholders together in order to ensure the active participation
- Change in access to information: there cannot be an implementation of citizenship rights without a participatory approach and without a focus on access to information of the disabled (adapted equipment, "texts in easy to read language", etc.). We need to systematically develop tools for a better understanding of the context and facilitate the choice.

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- Changes in the evaluation of services where all the stakeholders must be involved, including users.
- Change of the indicators to measure the quality of services: they must include items about quality of life, quality of care, the reality of the social bond, the legal capacity (for a practical implementation of their rights).
- Change of the roles, the positions and the functions of the stakeholders. This also concerns the role of the parents and families.
- Change in training of the support staff working with disabled people: recommendations in this direction have been made in various ARFIE projects, as in the recent Leonardo partnership CQ 2 (*Professional evolving know-how practices: Citizenship for people with disabilities. A challenge for the future training of professionals in the social care sector and their trainers*).

So there is no inclusion without special training of the user and without qualified training of the frontline and support staff working with the disabled.

Limits and pitfalls

The current discussion towards inclusion of the disabled and his/her rights should not be seen only in the context of paradigm shift or as a theoretical approach, based on good practice examples only in relation with “easy to fit” user profiles. It must be seen in context of the changing profile of the disabled with the concrete demands of the user characterized by an additional problematic such as:

- Mental disorders.
- Challenging behaviors rooted in social phenomena (relational ruptures, consumption of alcohol and drugs, etc.).
- Parenting couples with disabilities.
- Aging of the population.

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How to guarantee inclusion is challenging when addressing the limitations of the exercise of their rights:

- Limitations due to their skills (physical and mental).
- Limitations due to the institutional framework marked by centralized management services, despite all the efforts of the deinstitutionalization.
- Structural and operational limitation of the organization.
- Limitations due to the severity of the disability and severe dependence needs ; these issues still remain very controversial ! Even if this represents a real challenge, it should not be used as an excuse for inaction or as means of users' exclusion.
- Limits of available means : it would be wrong to argue excessively in favor of inclusion, assuming greater economic costs caused by this type of support.

If we think and we want "inclusion", we need to invest more resources in generic and community based services and networking, rather than exclusively in the specialized structures :

We should not only invest in qualified staff supporting children with special needs in kindergartens for example, but be pro-active so that qualified staff (teachers, etc.) in kindergarten are trained to accommodate children with special needs in an inclusive structured environment. Projects of this type are taking place in Germany (Hamburg) and A.P.E.M.H. is developing this path in Luxembourg through its resource center "Incluso".

- We do not only need to design endless specialised residential structures supporting disabled people, but also invest in community based living arrangements.
- We should not only focus on systematic reproduction of sheltered workshops since they cannot be the only solution for employment of the disabled person. We need to develop innovative services which could contribute to the different employment opportunities for the disabled people.

Raymond Ceccotto

General Director of A.P.E.M.H. / President of ARFIE



Social Model of Disability

Within the EU population today accounting to more than 494 million people, at least 16% are disabled and many of them have the ability and the will to work. The occurrence of disability is expected to increase, seen the current EU demographic situation and knowing that disability is also linked with aging. Many Member States have accessibility regulations and standards concerning the urban environment, transport, information and communication technologies, but only in some of them these provisions are compulsory.

Disability is an evolving concept (Article 1 of the UN Convention on the Rights of Persons with Disabilities).¹ The traditional approach to disability used to be based on the “medical model”, today instead the disability policies of the EU are based on the so called “social model of disability”. This social model, implying a recognition that it is the environment which is disabling and not the impairment per se, is the base of the EU Charter of Fundamental Rights, the European disability action plan 2003-10 and UN Convention on Rights of Persons with Disabilities.

Even if the EU legislation provides a common minimum level of protection in all Member States, the specific needs of people with disabilities are primarily addressed through national policies.

Each Member State prepares a national strategic reference framework (NSRF), which outlines its priorities for the use of Structural Funds of the Multi Annual Financial Framework in line with the Community strategic guidelines for cohesion and the Lisbon national reform programs.

EU Structural Funds

Through the “European Structural Funds”, the European Union reduces the disparities between the different EU regions. The Structural funds constitute over 35% of the EU budget and represent the most important financial instrument at EU level for social and economic development in the past multi annual financial

¹ Persons with disabilities are those ‘who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’



framework as within the new (2014-2020) to come.

The General Regulation of the use of the structural funds is compulsory for all the members and defines the criteria for the allocation of the European public funding such as: non-discrimination of disabled people full accessibility for disabled people and the obligation to include people with disabilities within the drafting, monitoring and evaluation of the Funds.

The Structural Funds designed to implement the above mentioned principles are :

- **ERDF (European Regional Development Fund)** whose primary objective is to equalize the main regional imbalances and to contribute to Europe's social cohesion.

The ERDF contributes towards the financing of :

- a) Productive investment which helps create and safeguard sustainable jobs, primarily through direct investment aid to small and medium-sized enterprises ;
- b) Investment in infrastructure ;
- c) The development of regional potential through measures supporting regional and local development.

The inclusion of the principle of accessibility for people with disabilities in the general regulation is extremely important for the implementation of infrastructure projects such as transport, built environment and telecommunications (including broadband and applications), and to support the active participation of persons with disabilities in regional development.²

- **ESF (European Social Fund)** addresses employment for all and social inclusion of marginalized groups

The ESF regulation emphasizes the objective to combat the social exclusion of disadvantaged groups, such as people with disabilities (Article 2.2 of the ESF regulation).

² Ensuring accessibility and non-discrimination of people with disabilities, European Commission, DG for Employment, Social Affairs and Equal Opportunities, January 2009



In the last ESF regulation, disability is addressed in three ways :

- Making specific reference to people with disabilities as a target group : “promoting pathways to integration and re-entry into employment of disadvantaged people, such as people with disabilities”
 - Providing for “acceptance of diversity in the workplace and combating discrimination in accessing and progressing in the labor market”
 - Requiring that annual and final implementation reports contain information on action to strengthen integration in employment and social inclusion of other disadvantaged groups, including people with disabilities ³
- **the European Cohesion Fund** : addresses issues such as : environment and transport

Recommendations on EU level

The European Union and its Member States need to ensure that European taxpayer money in the form of Structural Funds are invested in a manner that respects human rights and fundamental freedoms. The national authorities had much freedom in the management of the Funds within the financial framework 2007-2013 and that is why the organizations representing people with disabilities, and the European Commission and Parliament have asked binding measures for the Member States when managing the Structural Funds.

The European Commission and the Parliament have strongly defended the inclusion of ex-ante conditionality in the Regulation of the financial framework 2014-2020, since today there is a lack of trust towards the European Union and its goals such as : promoting territorial, economic and social cohesion due to the economic crises and how it was managed. Therefore, in the current social and economic context, it is of EU common interest that the Structural Funds are used to support the fundamental rights of citizens and social cohesion across the EU.

³ Camilla Parker and Luke Clement, The European Union Structural Funds and the Right to Community Living, The Equal Rights Review, Vol. Nine (2012)

DISABILITY POLICY AND EU STRUCTURAL FUNDS



In a nutshell

ARFIE demands that European Regional Development Fund (ERDF) and European Social Fund (ESF) are used to support the development of community-based living, since investing in health and social infrastructure contributes to regional and local development and increases the quality of life of all EU citizens.

Structural Funds can represent a great opportunity of financial and technical support to assist Governments in planning and implementing their deinstitutionalization strategies and in developing the community-based arrangements. Nevertheless, the use of Structural Funds, in training of the support staff working with disabled, in developing employment opportunities for the disabled and in granting accessibility within the built environment and the communication technologies, has proven to be a successful tool in guarantying citizenship rights for the whole EU population and contributed to be even closer to achieving social justice and inclusive EUROPE for ALL.

Daniela Janeva

Program Director - ARFIE - Bruxelles

CONCLUSIONS



Provision of quality services to disabled persons in today's budget constraints policy is at risk, since these services are strictly linked to public funding. There is a great preoccupation on how we could avoid low quality services when supporting persons with disabilities in these years of fiscal consolidation and austerity. Health and social services play an important role in the **employment growth** of the EU since the job creation potential in these services grows much faster than in other sectors, seen the demographic situation in the EU.

For this reason we demand the European Institutions to ensure and pursue legal and financial framework permitting to service providers to deliver quality services to disabled people as they represent a strategic tool for fighting poverty and exclusion.

It is of EU common interest that the Structural Funds are used to support the fundamental rights of the disabled such as: **prevent re-institutionalization**; **guarantee accessibility** - designed for all; **promote employment opportunities** that will permit long term inclusion of the disabled; **promote participation of people with disabilities at all levels** and guarantee that they are involved in all stages of the policy development ("Nothing for us without us").

Since disability is in continuous evolution, the EU, through the use of the European Social Fund, should oblige Member States to promote **continuous training of the staff** working with disabled people in order to guarantee quality service provision. Regulation of all the care workers, better social protection benefits and rethinking of the adequacy of the services provided should be a MUST in order to guarantee equal citizenship rights for ALL.

We demand the European Institutions to explicitly discourage Member States into adopting austerity budget constraints in social and care series since investing in social infrastructures means ensuring dignity life and saving tomorrow's costs and expenditures.

We welcome the **Social Investment Package** as a great example into investing in meeting the EU citizens' needs since the EU clearly needs more social policy that guarantees more inclusion and not less. Long-term investment should be directed to **de-institutionalization of services** for disabled people and through the

CONCLUSIONS



modernization of social protection systems. The EU should urge Member States to include in their National Reform Programmes the guidance provided with a particular attention on increased focus on social investment in their social policies.

Through the involvement of all the stakeholders, especially social and civil society organizations, the EU could promote good governance and reinforce the monitoring tools to measure the progress made by Member States by integrating a Social Protection Performance Monitor (SPPM) into the Annual Growth Survey.

Research in innovative health and social (as already foreseen in HORIZON 2020) services for disabled should concentrate on his/her abilities in order to develop know-how able to grant **active participation** of the disabled and his/hers implementation of citizenship rights (as foreseen in art. 29 and 30 of UN CRPD). Active participation is a great tool to promote empowerment of the person with disability and his/hers participation shall be promoted in all circumstances regardless of the nature and the degree of disability.

Since unemployment of disabled people is two times more in comparison with not disabled, the EU should insist on adopting measures of binding nature within the employment provision policy for disabled people of its Member States.

Alternative employment opportunities and solutions to the sheltered workshops, in particular, supported employment policies with job coaches should be promoted by public funding since we need to guarantee that the disabled has the possibility to choose as he/she represents the main actor and decision-maker of his/her life path (self-determination).

Thus, the EU through the European Regional Development Fund and the European Social Fund should stress Member States into conducting a policy of employment and inclusion for all in order to guarantee a full implementation of the UN CRPD within its Member States countries.

CONCLUSIONS



We would like to remind that the EU disability policies such as: EU Charter of Fundamental Rights, the European disability action plan 2003-10 and UN Convention on Rights of Persons with Disabilities are based on the so-called “social model of disability” which implies a recognition that it is the environment which is disabling and not the impairment per se. For this reason fighting discrimination of disabled people and promoting self-advocacy of the same needs to be compulsory.

The Structural Funds in disability policy should be directed toward investment in :

- developing community-based arrangements (art 19 UN CRPD);
- creating vocational training courses for the social worker and formal recognition of the skills needed;
- granting accessibility within the built environment and the communication technologies;
- assuring applied and inclusive research to improve the quality of life of people with disabilities

in order to achieve social justice and an inclusive EUROPE.

Daniela Janeva

Program Director - ARFIE - Bruxelles

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**ARFIE is a European network of partners
active in training, research and quality service
provision for people with a disability**



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