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EUROPEAN REPORT

101: INCLUSION CHAMPION PROFILE DESK AND FIELD RESEARCH

Work-Aut

Leveraging WBL to foster professional inclusion of people affected by Autism Spectrum Disorder

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1.Summary

This European report is the product of a joint research carried out by all partners of Work-Aut Project (Work-Aut: Leveraging WBL to foster professional inclusion of people affected by Autism Spectrum Disorder - project n. 2020-1-NO01-KA204-076508).

The research comes from both the main findings of the National Reports (processed in Bulgaria, France, Germany, Italy, Norway) drawn up by the project partner organization both on the basis of the existing literature and the collection of good practices at several level (local, national, European).

The ultimate purpose of the report is to provide inclusion professionals, human resources managers and companies with information, input and an overview on the policies and welfare currently in force in Europe regarding the inclusion in the labour market of people affected by Autism Spectrum Disorder (ASD).

This will help build the capacity within companies to make cultural, operational and protocol changes in order to create a more productive and successful work environment involving people with ASD.

After describing the main aim and scope of the European Report, a whole chapter is dedicated to the inclusion in the labour market of people affected by ASD in Europe with a specific focus on the policies, the strategies and the legislative framework: the research started from the international dimension of the inclusion in order to better figure out the European Union strategies into this dimension. Furthermore, it has been highlighted that there is no uniformity in terms of approaches from each single national EU context to the labour inclusion of people affected by ASD.

The second chapter is dedicated to the presentation of good practices at European level on professional inclusion of people affected by Autism Spectrum Disorder. Many good practices have also been identified at National level in partnership countries and they are available in the National reports.

In the end, since most of the work has been carried out by each partner into their own National reports (Italy, Norway, Bulgaria, France and Germany), main findings from them have been summed up in order to facilitate the creation of the Inclusion Champion skills profile, the last activity planning for the elaboration of this first project output.

2. Aim and scope of the European Report

Work-Aut - Leveraging WBL to foster professional inclusion of people affected by Autism Spectrum Disorder (http://www.workauteurope.com/) is a project co-funded by the Erasmus+ Programme of the European Union aiming at facilitating people affected by ASD to get access in the labour market.

One of the priority areas of the <u>European Disability Strategy 2010-2020</u> aims at raising the employment rate of persons with disabilities working in the labour market. They represent one sixth of the EUs overall working-age population, but their employment rate is comparatively low.

Employment contributes to social inclusion by providing opportunities for social participation.

Autism covers a wide range of symptoms, skills and levels of disability and is therefore referred to as a disorder. However, because of the shortcomings they may display in social interaction and other fields they are often considered 'inadequate' for regular employment and are therefore reduced to further social exclusion episodes.

Facts coming from National reports have been matched up in a European report. This report has also been informed by including some facts and findings as well as good practices when available, from European countries outside the partnership.

The project's outputs and activities have been informed by the overriding objective of developing a more open and inclusive labour market and fostering participation of people affected by ASD through the development of new competences for professionals of the recruiting and employment processes.

As a starting point for the design of the training material and for the identification of skills and abilities to be developed to promote the professional inclusion of people with Autism Spectrum Disorder (ASD), this report has been created, based on research and focused on the collection of good practices at several levels.

The research aims to provide an overview of the situation in the European Union countries, as well as the basis for an overview at international level, and to highlight the gaps and needs in the field of professional inclusion of the target group of the project.

The report represents the basis on which the project partners will build resources and training materials but at the same time it can be used to sensitise policy makers, companies, training bodies and employment centres about the needs of people with ASD and about the actions and strategies needed to ensure their greater integration into the labour market. It will also provide information and help to understand both how they can improve their services and facilities to meet the needs of the target group.

This will help the project achieve its goals and a broader impact aimed at improving the social inclusion of people with ASD who currently feel excluded from many traditional training paths and from several job offers.

Certainly, the European Report will help build the capacity within companies to make cultural, operational and protocol changes in order to create a more productive and successful work environment involving people with ASD.

In terms of project outcomes, the Report constitutes the starting point for the definition of the Inclusion Champion Profile and the support resources that will be produced within the first project output (IO1) will help organisations to develop the role of "Inclusion Champion" and to sensitise companies on the added values of working with ASD people. Moreover, the definition of a Work Based Learning (WBL) path for job seekers affected by ASD will design a tailor-made training pathway for the target group taking into account characteristics, strengths and weaknesses, specific needs and thus provide an effective tool for the promotion of professional inclusion.

3. Inclusion in the labour market of people affected by Autism spectrum disorder

In Europe, it is estimated that 5 million people are on the autism spectrum, it means that 1% of the European population is on the autism spectrum.

Their access to education and employment is a human right and is a keystone of social inclusion: they are linked and many autistic people experience barriers in both areas. It results in poor employment outcomes.

Autism is a complex disability that affected people experience for their lifespan. It is a spectrum and affects each single person in a different way.

The most relevant displays are:

- Problems with social interaction, communication and imagination
- Significant sensory sensitivity
- Limited and repetitive sets of attitudes, activities and interests
- Cognitive difficulties

People affected by ASD face discrimination in several aspects of social and individual life, such as education and vocational training.

They are often unemployed: their employment rate is less than 10% and most of the employed persons works in precarious jobs and are low payed. It also increases their risk of poverty and social exclusion.

Most of autistic people with support needs are not in education, employment and training and are not counted in statistics (i.e. live in institutions or in unsupported families).

4. Policies, strategies and legislative framework

The framework in which the policies and the strategies are addressed is different depending on the level they are conceived.

International level

- UN Convention on the Rights of People with Disabilities - Article 27: Work and Employment: "Opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible".

In 2015, the Committee on the Rights of Persons with disabilities (CRPD Committee) addressed observations to the EU on Art. 27. EU was recommended to take effective actions to measure the employment of persons with disabilities and increase their employment rate in the open labour market, especially for persons with intellectual and/or psychosocial disabilities, including by providing training for member States on reasonable accommodation and accessibility in the context of employment.

- Sustainable Development Goals

Goal 8- Promote inclusive and sustainable economic growth, employment and decent work for all.

Goal 5: Achieve full and productive employment and decent work for all women and men, including for persons with disabilities

Goal 6: substantially reduce the proportion of youth not in employment, education or training (NEET).

apprenticeships are often closely connected to workplace actors.

European level

- Employment Equality Directive Directive 2000/78/EC well known as "Employment Equality Directive". It prohibits discrimination on grounds of religion and belief, age, disability and sexual orientation and covers the fields of employment, vocational training, membership of employer and employee organisations.
- European Pillar of Social Rights

Pillar 4. Active support to employment: Everyone has the right to timely and tailor-made assistance to improve employment or self-employment prospects. This includes the right to receive support for job search, training and re-qualification. Everyone has the right to transfer social protection and training entitlements during professional transitions.

Pillar 17. Inclusion of people with disabilities: People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.

On March 17th 2021, the European parliament asked the Commission on the following questions:

1. What will the Commission do to improve the prospects for personal development and the employment outcomes of autistic people, specifically with regard to protection under legal frameworks covering social security, working conditions, minimum wages and non-discrimination in institutions; individualised and specialised support in education and training, and in the transition between these and employment; individualised approaches to identify needs and improve employability (including with modified recruitment procedures and evidence-based employer training courses), to ensure quality and inclusive employment with equal pay, as for persons without disabilities, as well as reasonable accommodation; the use of assistive technology; and use of EU funds in this context?

- 2. How concretely will the Commission improve and ensure the collection and monitoring of quality disaggregated data of the employment situation of autistic people, including those with co-occurring conditions, other disabilities and in institutions and sheltered settings?
- 3. What concrete measures does the Commission propose in order to take into account the quality of life, diversity of the situation and needs of persons on the autism spectrum, and the effects of the pandemic and of the intersectional discrimination they face in the areas of, among others, education, housing, employment, social protection and inclusion, and in order to ensure that the Member States address their specific needs when implementing the EU Disability Strategy?

5. Good practices at European level on professional inclusion of people affected by Autism spectrum disorder

Title of the good practice	AUTISM EUROPE
Country	All EU Countries
Level	□Local □National X European X International
Responsible organization	AUTISM-EUROPE aisbl
Year/Duration	Since 1983
Website of the practice	<u>www.autismeurope.org</u>
Description of the good practice	Autism-Europe is an international association whose main objective is to advance the rights of autistic people and their families and to help them improve their quality of life. It ensures effective liaison among almost 90-member autism organisations from 38 European countries, including 25 Member States of the European Union, governments and European and international institutions. Autism-Europe plays a key role in raising public awareness, and in influencing the European decision-makers on all issues relating to the rights of autistic people. Self-advocates and parents play a central role in the organisation to ensure that the views and interests of persons with autism are adequately reflected in their work. They are recognised by the European institutions as the voice of autistic people and their families in Europe. To maximise our impact on the European Union's policies, Autism-Europe also works in strategic coalitions with organisations that share the same concerns and goals. They are also regularly consulted by the World Health Organisation (WHO) and cooperate with the United Nations (UN). Autism-Europe also enjoys a participative status (for non-governmental organisations) with the Council of Europe and in July 2002 lodged a collective complaint with the European Committee of Social Rights, becoming the first disability NGO to undertake such action.

Target group(s)	People affected by ASD and their families, autism organisations.
Impact	The organization works with its members to: - Advocate for the rights of people with autism before the European institutions; - Monitor European laws and policies; - Promote appropriate care, education, training and employment, living support, adapted medical and social services, professional diagnosis, early intervention, protection from discrimination and better social inclusion to foster the well-being of people on the autism spectrum; - Promote the exchange of information, good practices and experience in the field of autism; - Promote awareness of autism Hold a triannual international congress to share the latest research and best practices regarding areas such as therapies, support, social inclusion and services provision. Each year, it collaborates with its members in conducting campaigns to raise awareness about autism on World Autism Awareness Day (April 2).

Title of the good practice	INCLUSION EUROPE
Country	EU Countries
Level	□Local □National X European □ International
Responsible organization	INCLUSION EUROPE
Year/Duration	Since 1988
Website of the practice	www.inclusion-europe.eu
Description of the good practice	Inclusion Europe is a European association, made up by 78 members in 39 European countries. Its main objectives are: - let people with intellectual disabilities enjoy equal rights and fully participate in all aspects of life - let family members of people with intellectual disabilities can be just that – family members -make the interests and concerns of people with intellectual disabilities and their families considered in all policies affecting them It fights for equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of society. Key values: - Respect for people with intellectual disabilities, their opinions and choices Solidarity between weaker and stronger persons, generations and organisations Inclusion of people with intellectual disabilities and their families in all aspects of society as a result of respect and solidarity.
Target group(s)	People with disabilities and their families, inclusion organisations.

Impact	As a European association, it works in many different areas: - Running campaigns and projects on topics relevant to people with intellectual disabilities and their families - Organising events for people with intellectual disabilities, family members and professionals in different European countries - Supporting self-advocacy and the development of easy-to-read - Influencing European policies in different policy areas - Connecting its members so they can exchange experiences and good practices.
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Title of the good practice	Autism Spectrum Disorders in the European Union (ASDEU)
Country	EU Countries
Level	□Local □National X European □ International
Responsible organization	ASDEU Consortium
Year/Duration	2015/2018
Website of the practice	<u>www.asdeu.eu</u>
Description of the good practice	Autism Spectrum Disorders in Europe (ASDEU) was a three-year (2015-2018) programme funded by the European Parliament to research autism prevalence, costs, diagnosis and interventions throughout Europe. Its overall aim was to find ways to improve care and support for people with the condition and their families. It is the most comprehensive clinical and policy autism spectrum disorder (ASD) research ever done in Europe, generating important findings that will impact the development of future policies both within European Union (EU) member states and at the European Commission level. ASDEU is also the first multi-national prevalence study of ASD in Europe.
Target group(s)	Policy makers, people affected by ASD and their families, ASD organisations.
Impact	 Study the prevalence of autism in 12 countries Analyse the economic and social costs of autism Develop proposals for early detection programmes Validate biomarkers for the disorder Train professionals Improve understanding of diagnosis, comorbidity and effective care and support for adults and senior citizens with autism Propose policies to promote harmonised support for people with ASD across member states

6.The Work-Aut project and main findings from the National Reports

Work-Aut - Leveraging WBL to foster professional inclusion of people affected by Autism Spectrum Disorder (http://www.workauteurope.com/) is a project co-funded by the Erasmus+ Programme of the European Union aiming at facilitating people affected by ASD to get access in the labour market. Work-Aut main objetives are:

- to raise awareness of companies, labour market institutions, employment offices, on the need to adapt recruiting systems to facilitate the professional inclusion of the target group;
- to empower employment officers, job counsellors and HR managers to better understand how to improve their governance structures, competences and institutional culture in reference to professional inclusion of people with Autism Spectrum Disorder (ASD);
- to bridge the gap between the target group and the labour market institutions and organisations, helping them better engage with each other;
- to provide a freely accessible, permanent set of resources and tools for the continuous development of employment institutions, companies, HR managers through the development of new competences and skills.

3 Intellectual outputs will be produced throughout two years:

- IO1 Inclusion Champion Profile
- IO2 Work-Based learning pathways
- IO3 Training Courses

The envisaged impact for the first main target group - employment officers, job counsellors and HR managers, is that they will be able to improve the quality and widen the scope of the services they offer and thus improve their skills and raise their awareness. The impact for the second target group - i.e. the young adults affected by ASD, will be their better employability. The connection between the two target groups will also be guaranteed by the creation of the European Pool for inclusion - a platform connecting job seekers, companies and career practitioners.

Five National Reports have been produced by partners (Norway, Italy, Germany, Bulgaria, France) and they have been based on desk and field research activities.

The desk one refers to the state of the art of the main studies in the field of professional inclusion of young people affected by ASD, as well as the legal and regulatory frameworks at EU, national and local level.

A specific section focuses on the collection of at least 3 good practices at EU, national and local level of labour inclusion of people affected by ASD in order to highlight needs and problems in this field.

The field one has been conducted through interviews addressed to relevant stakeholders: professionals and advocacy groups.

National Reports have been mainly addressed to companies, HR managers, employment officers, job counsellors, policy makers and institutions, educational institutions.

<u>Main findings from the National Reports</u>

A new job is something stressful for everybody. Especially for people affected by ASD who may be facing several challenges connected to the symptoms of their status.

Problems with social communication and interaction are some the most relevant barrier to the workplace integration. People with ASD may be troubled by close distance to other employees, and by the expectation to socialise. That is the reason why the awareness raising among the members of the work team and managers is necessary to assure that the needs of the employee with ASD are understood and respected.

Somebody could have also problems in expressing themselves verbally and knowing the others. To ease communicate with the employees affected by ASD, open, concrete, clear and complete language must be adopted, eluding double senses, humour, metaphors or gestures. Sometimes, it is useful to have the intervention of a tutor negotiating as an intermediary between the people with ASD and their collaborators: the tutor can support strongly the communication and promote the appreciation of diversity in the workplace.

Main barriers for people affected by ASD in accessing the labour market:

- Social, communication and learning problems
- Lack of access to several levels of education and vocational training pathways due to school drop off and exclusion and shortage in supporting services
- Limited executive functioning
- Barriers in the recruitment process
- Prejudice amongst employers
- Lack of adequate support
- Sensory hypersensitivity: Noises, smells and visual impulses of the workplace may be very irritating and, in some cases, may lead to panic or even nervous tension.

Main strengths of people affected by ASD:

- Attention to details and accuracy
- Analytical Methodical approaches
- Deep focus and concentration
- Detail-focused
- In depth knowledge
- High level of skills
- Fact finding
- Observatory skills
- Excellent long-term memory
- Integrity, honesty, loyalty, commitment
- Determination
- Creativity
- Innovative solution

The main findings from the National researches carried out shows that there are many features in common concerning the better inclusion of people affected by ASD in the labour market. First of all, it is important that programs and pathways helping people get jobs (at different level) must take into account strengths of autistic people. This employment strategies should be person-cantered and individualized to identify needs. Getting people affected by ASD accommodated in the workplace in crucial: it sometimes needs a transformation of the work environment (spaces, lights, sounds, etc.) and the work schemes. Everything must be done to improve the quality of life of employees according to their need and what they want.

Furthermore, the learn-by-doing experience is bottom-line: it is key to develop programs to gain experience and develop employment outcomes.

Bulgaria

When it comes to inclusion of people affected by ASD in the labour market, it is important to mention that there are no policies or strategies in Bulgaria specifically targeted to people with ASD. People with ASD are included in a more general context, that of people with disabilities and mental health problems. The legislative framework and strategies in Bulgaria address this broader and more general context. The preliminary desk research has revealed that the main efforts in terms of integrating people with ASD are directed mainly towards early life initiatives which aim to help children with ASD get access to appropriate educational opportunities that would prepare them for better social and professional integration later on in life. There are different organisations, mainly in the non-government sector which try to implement various educational initiatives for children with ASD, but it seems there is no unified state policy of providing specialised education to people with ASD.

The inclusion of people affected by ASD in the labour market is still a highly underdeveloped area in Bulgaria. There are no established clear pathways, just a national strategy directed towards ensuring employment opportunities to people with disabilities, which currently has more of a documental value than a practical application. Also, the designated percentage of people with disabilities that could potentially get employment access is very low and dependent on the size of the company/organisation that would provide employment.

Though positive, the examples of such practices are still very few and mainly existent due to the specific company's overall global policy and not so much on national, government-provided opportunities.

Germany

The number of people with disabilities suffering from unemployment is twice as high as those among people without disabilities whereas the differences between those two groups even increase with a higher age according to data from the German Employment Agency. There are only estimations on how many people with ASD are included in the labour market. In 2013, probably only 5% of people with autism are included in the general labour market in Germany, around 40% to 65% are employed in specific places for disabled persons, whereas the rest of them are not in employment. A study from 2017 gives similar indications, claiming that around 5% to 12% of people with ASD in the working age between 15 and 64 years have permanent, insured employment. The majority of this group is probably suffering from atypical autism and Asperger.

Another strategy followed in Germany is the one of "workplaces for people with disabilities". These are workplaces that were specifically developed for people with disabilities who would otherwise not be able to participate in vocational training and apprenticeship. Currently around 320.000 adults are working in these facilities, among them 30.000 are involved in the vocational education area, whereas 270.000 are participating in the field of work. The remaining people receive special care and support due to their severity of the disability. The workplaces enable an individual in-company training, an orientation phase as well as the support with the help of a job-coach.

As the desk and field research has clearly demonstrated, the topic of the inclusion of people with ASD in the working life is a broad field. In Germany, there are many regulations and strategic approaches available to support this aspect, however, as especially the insights of people working in this field shows there is still a lot of potential to fill in.

France

In France, only 0.5% of people with autism have a job in an ordinary environment (autism strategy 2018-2022). It would seem, however, that this figure cannot really be verified and the only existing figure would be that of 23,000 autistic ESAT users, or around 5% of adults (Court of Auditors report). Different aids are possible for people making a request for recognition of the quality of disabled worker (RQTH) at the Departmental House of Disabled Persons (MDPH), they will be able to have personalised support to identify the possible aids and achieve their professional objective, offered by the public employment service (Cap Emploi, Pôle Emploi, etc.); benefit from the supported employment system, including medico-social monitoring and professional integration, from job search to taking up a position; prepare for the interview with a view to being hired, via a support service for social life (SAVS) or an association; request arrangements for taking a professional competition; request the intervention of a support person in employment (also called "job coach", supported employment counsellor, integration counsellor, consultant, etc.) This support aims to prepare and support an autistic adult in employment thanks to individualised support.

But despite a few examples of people with autism with promising employment outcomes, many of them continue to experience challenges and difficulties in staying in employment. This is in part driven by role models. service that continues to focus on disability reduction, ignoring the strengths of people with autism, perpetuating low expectations and leading to poor employment outcomes. The difficulties encountered by people with autism in employment are directly linked to the characteristics of autism and are reflected as follows: difficulties in mastering the application process, difficulties in following a sequence of instructions or instructions, difficulties in communicating and interacting with colleagues, difficulties in integrating into the corporate culture.

Norway

There is a very clear need for more competence among people who facilitate ASD persons over to work, and among staff at the new workplace. There is also a need for more research among adult ASD persons.

A mentor is often mentioned in Norwegian research, a person that supports the adult ASD person at work. The mentor is also in need for more competence about ASD.

In the national report, NOU 2020:1, it is suggested that an online course about ASD would be helpful if developed.

In 2020, Norway had its second public report concerning ASD, NOU 2020:1. The first was delivered in 1988. The aim of the report was to put light on services specially aimed for this group. A lot has changed since the last national report in 1989, and Norway has ratified several international agreements. The UN Convention on the Rights of Persons with Disabilities was ratified by Norway in 2007. Through this agreement, Norway has committed to ensuring services for this group and ensuring co-determination. Within health, special education, formal education, and labor there are tremendous development and changes for this group. The report describes these changes.

Norway has a legal framework which should indicate that persons within the ASD definition are in good hands. But the NOU shows that training and knowledge about the diagnosis are requested among many parts, also among persons with the diagnosis. Work situations and adulthood is especially in lack of research.

Italy

In Italy, the obstacles to the work placement of people with disabilities in the labour market

are still notable. In the two-year program for disability presented by the Government

In 2013, the failure of Law 68/99 is implicitly recognized by describing the dramatic situation in the country concerning the right to work of the disabled people. If the unemployment rate of the disabled people is 4 times higher than the others, the relevance of people with ASD becomes even more serious: the social and work integration of people with autism is believed to be so complex, that, according to a recent Censis survey, only one person out of 10 with autism spectrum disorder find work today.

The difficulties arise not only due to the inadequacy of the legislative instrument, but also due to the absence of accompanying services specialised in the insertion of the disabled and, in particular, of people with autism in the labour market and in the transition phase.

7. Conclusions

The European Report shows that in Europe different approaches and strategies have been adopted in fostering the inclusion of the people affected by ASD in the labour market.

The national rates of employed people with ASD are different from one country to another but still low.

Starting from the legislative frameworks, it seems that there is no uniformity between the EU analysed countries. Most of the countries have no specific legislation addressed to the inclusion of people with ASD, but it is regulated in general as for disabled people.

Moreover, workers' welfare in general is also approached in different ways by each government and a more uniform scheme is also needed in this field.

That is why strong and clear guidelines are required to be adopted and agreed at EU level: they will help both national governments to properly elaborate regulations and both institutions, associations and non-for profit organisations to inspire their efforts and committment in the field of the inclusion of people with ASD.

Furthermore, companies are still far from perceiving the inclusion of people with ASD as an added value: it depends on the lack of knowledge and awareness campaigns but also on the absence of tailored programmes at national and local level aiming at structuralizing the employment of people with ASD.

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