# AUTISM AND WORK Together we can





A report on good practices in employment for people with autism from across Europe.

# **Autism-Europe**

Autism-Europe is an international association whose objective is to advocate for the rights of people with autism spectrum disorders (autism, ASD) and their families, to help them improve their quality of life.

This is achieved through:

- Representing people with autism before all European Union institutions;
- Promoting awareness of appropriate care, education and well-being for people with autism;
- Promoting the exchange of information, good practices and experience in the field of autism.

Autism-Europe is the umbrella organisation for a network of more than 80 associations of parents of people with autism across 30 European countries. Autism-Europe has established a structured dialogue with the institutions of the European Union and the World Health Organisation, to advocate for the rights of people with autism. To maximise its impact on European Union policies, Autism-Europe also works in strategic alliances with other relevant organisations, including the European Disability Forum and the Platform of European Social NGOs.

More information: www.autismeurope.org



#### Design and printing by people with autism

#### **PASPARTA Publishing (Czech Republic)**



PASPARTA staff at work.

This report has been designed by employees who have autism at PASPARTA Publishing, a social enterprise founded by the autism organisation, APLA Prague, in the Czech Republic. Its objective is to offer employment opportunities to people with autism in an adapted environment where they can make use of their unique skills. PASPARTA publishes books on education, special needs education, sociology, law and other topics.

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A report on good practices in employment for people with autism from across Europe.

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Some of the diverse employment options for people with autism from across Europe. Photos from Autisme La Garriga (Spain), APLA (Czech Republic), Autismus Karlsruhe (Germany) and ©iStock.com/1001Nights.

#### With thanks to the following contributors:

Evelyne Friedel, Miren Hurtado, Sandra Juncu, ANGSA, ANGSA Liguria, APLA, APPDA Coimbra, The Astangu Vocational Rehabilitation Center, Auticon, Autisme La Garriga, Autismo Andalucía, ESAT Les Colombages, The Finnish Association for Autism and Asperger's Syndrome,
Fondazione Oltre il Labirinto Onlus, GAUTENA, The Icelandic Autistic Society, Greenbridge Growers, The Kuwait Center for Autism, Laboratorio di Esplorazione Multimediale, L'Oréal Italy, The National Autistic Society, The Orchardville Society, Passwerk, PASPARTA Publishing, Rainman's Home, Salva Vita Foundation, SAP, Specialisterne.

This report was published in 2014 by Autism-Europe.

#### This report and further information on the topic of autism and employment are available on the Autism-Europe website: www.autismeurope.org

Ce rapport est aussi publié en français. Si vous souhaitez recevoir ce rapport en français, veuillez en avertir notre secrétariat l'adresse ci-dessus

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This report was published with the support of the Directorate-General Justice of the European Commission, under the European Community Programme for Employment and Social Solidarity, PROGRESS. The information contained in this publication does not necessarily reflect the views or opinion of the European Commission.

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# FOREWORD



Despite over seven decades of research in autism since the condition was first described by Kanner in 1943, studies of adults with autism are few in number compared with the many thousands of studies on children. Research on treatment is particularly insufficient, and the lack of appropriate interventions for adults with autism has many negative implications. Rates of mental health problems are significantly raised, levels of dependence are high, social inclusion is limited and too many adults face a lifetime of loneliness and isolation. As well as the costs to individuals and their families, the cost to society is also significant. Thus, a recent economic analysis<sup>i</sup> suggests that autism costs the economies of the United States and the United Kingdom \$175 billion (£104 billion) and £32 billion per year respectively; more than any other medical condition and greater than the cost of cancer, strokes and heart disease combined. The costs are particularly high in adulthood because of the huge loss in productivity due to lack of employment. Indeed, unemployment rates among adults with autism are significantly higher than among adults with intellectual disabilities or other developmental disorders.

It is against this background that the present report was compiled. It highlights the unacceptable situation with regard to employment for people with autism, and the challenges they face in finding or keeping appropriate jobs. For, despite the difficulties associated with the condition, many individuals possess particular strengths or areas of skill that have considerable potential in the workplace. Such a waste of potential is inequitable and highly discriminatory.

However, the report goes much further than simply documenting the many difficulties experienced. Instead it highlights strategies that can be used to help adults with autism enter the workplace. The focus throughout is on gaining successful employment in the open labour market and a range of different programmes across Europe are described. These vary widely, as is necessary for a condition as heterogeneous as autism, but the evidence shows that strategies to support individuals into and during employment, although initially relatively expensive, ultimately result in economic as well as personal gains.

As the report concludes, access to employment is a fundamental right, enshrined in the United Nations Convention on the Rights of Persons with Disabilities. It is the duty of society to uphold these rights and here we have many examples of how this can be achieved, to the benefit of both individuals with autism, their families, the organisations in which they work and society as a whole.

Patricia Howlin Emeritus Professor of Clinical Child Psychology King's College, London Across the European Union, 11.5 per cent of adults are currently unemployed<sup>ii</sup>. For people with autism, the unemployment rate is much higher – studies indicate between 76<sup>iii</sup> and 90<sup>iv,v</sup>, per cent. This situation is clearly unsustainable and requires urgent action. The European Union has signed the United Nations Convention on the Rights of Persons with Disabilities, obliging its Member States to take action to address the needs of people with disabilities, including autism, in all aspects of their lives, including employment. This report outlines the difficulties faced by people with autism when trying to gain and maintain employment and provides many examples of initiatives that have been created to employ people with autism that can serve as positive examples for others to follow and build upon.

People with autism usually struggle to gain and maintain employment for a range of reasons. The most obvious of these is their inherent difficulties with communication and social interaction, which affect their abilities to understand employers' expectations and communicate effectively with managers and colleagues. The deficits in executive functioning and hyper-sensitivity to sensory stimuli, such as sound and light, that some people with autism experience can also make it difficult to get, an/dor keep, a job. Yet, the greatest challenges that people with autism face in relation to employment do not come from within. The greatest challenges they encounter are usually a lack of access to opportunities and stigma and discrimination in relation to their condition.

These barriers to employment are raised long before a person with autism starts looking for a job. Across Europe, there is a serious lack of adapted education and training that could enable people with autism to gain the vocational, social and communication skills that are required for work. When a person with autism does seek employment, regardless of whether they managed to gain a relevant education or not, they are often confronted with stigma and discrimination related to their autism. Even if a person does not reveal the fact that they have autism to a potential employer, many will be turned away because employers interpret their difficulties in communication and social interaction as clear signs that they are not suitable employees, rather than seeing that the individual needs specific forms of support to enable them to perform well in the job. For those who do manage to gain a job, keeping it is another challenge. The combination of inherent difficulties, lack of support and social attitudes can be overwhelming for a person with autism.

Despite the internal difficulties and societal barriers that confront people with autism, they have many strengths that can make them potentially outstanding employees. These can include the ability to focus on details, the ability to excel at logical and repetitive tasks, and the tendency to be very loyal and reliable.

To enable people with autism to gain employment and fulfil their potential at work, support is essential. A range of approaches to, and structures for, providing this support are emerging around Europe. This report outlines some innovative practices in this field, including individual transition planning from school to further education to employment, adapted further education and training, work experience programmes, adapted recruitment processes and diverse forms of support in the workplace.

Support in the workplace can include making adaptations in cooperation with the person with autism to accommodate their difficulties and capitalise on their strengths, such as adjusting the job description, working hours, workplace communication practices and the physical work environment. It can also include providing assistance with transport to and from work, and/or using assistive technologies such as tools for communication through text and images and tools for daily scheduling. One of the most significant emerging forms of support for people with autism at work is the practice of having

identified support people such as 'job coaches' or other staff members who are designated to assist a person with autism with the difficulties they encounter.

Of course, the types of support that are required depend on the needs of the individual with autism as well as the nature of the organisation for which they are working. From assisting people with autism to participate as individuals in the mainstream labour market, to creating businesses specifically designed to employ the strengths of people with autism, a diverse range of approaches and structures for successfully employing people with autism are emerging to provide good practice case studies for others to follow.

When considering the possibilities for people with autism in relation to employment, it is essential to ensure that their rights are at the centre of our concerns. People with autism have the right to employment in inclusive settings and the right to reasonable accommodation and support to enable them to work effectively. These rights are described in detail in Article 27 of the United Nations Convention on the Rights of Persons with Disabilities. Moreover, the solutions developed to provide support in employment for people with autism should always be tailored to each person's individual needs. The employment solutions for people with autism must be as diverse as the individuals themselves. At all times, people with autism and the parents or quardians of those in need of a high level of support, should be empowered to make informed decisions about their employment. Given that like all other people, the needs and abilities of people with autism in relation to employment can change over time, support should also be provided on an ongoing or as required basis, from preparation for employment through to retirement. In the evolving field of autism and employment, we must continuously develop our knowledge and confront stereotypes about people with autism, ensuring that the solutions developed are based on evidence, not assumptions, and that positive emphasis is placed upon their abilities rather than their disability.

Across Europe, many organisations are putting these principles into action. Yet, as the vast majority of adults with autism remain unemployed, further action is urgently required. It is not only the role of progressive employers and autism organisations to create pathways for people with autism into employment, it is also the role of national governments. The European Union and all of its Member States have signed, and or ratified, the United Nations Convention on the Rights of Persons with Disabilities, obliging them to take action to implement the rights of people with disabilities in all aspects of life, including employment.

Supporting people with autism to gain and maintain employment undoubtedly entails costs. Education, training and supported employment programmes all involve public expenditure. This public expenditure must be considered as an investment. When an organisation employs a person with autism, it is not simply an act of charity or corporate social responsibility, there is a mutual benefit – given the right support, the employee with autism becomes an integral part of a team of employees that helps the organisation to succeed. In addition, when people with autism are employed, they are not only able to support themselves (or at least partially support themselves) financially, they are also able to contribute directly to society through their work and through their tax contributions. When a person with autism is employed, it is clearly a sound investment benefiting not only people with autism, but the organisations they work for and society as a whole.

Above all, for people with autism, employment is about more than just having an income – it enables them to become active members of society and to live more fulfilling and independent lives.

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# INTRODUCTION

Today, between 1 in 100 and 1 in 150<sup>vi</sup> children are diagnosed with autism, amounting to around 3.3 million people with autism in the European Union. While access to diagnosis and therapies for children with autism is improving across Europe, in most regions, they grow up to face widespread unemployment and little or no support as adults.

Studies have shown that between 76<sup>vii</sup> and 90<sup>viii,ix</sup> per cent of adults with autism are unemployed. Perhaps these statistics are not surprising, given that people with autism commonly experience difficulties with the social and communication aspects of work, including job interviews, understanding managers' instructions, managing their time and interaction with colleagues.

Yet, the barriers to employment that people with autism face are not only caused by their disability. They also face much stigma and discrimination when trying to get or maintain a job. Despite that, adults with autism often really want to work and can be exceptionally capable of doing particular jobs. A study in the United Kingdom showed that the vast majority of adults with autism who are currently unemployed and dependent on support from government and family members say they would like to work, with the right support.<sup>×</sup> They simply need assistance to overcome the barriers and difficulties they face.

This report aims to articulate the issues and difficulties faced by people with autism in relation to employment across Europe. In the context of the United Nations Convention on the Rights of Persons with Disabilities, it outlines various forms of support that can be utilised to enable individuals with autism spectrum disorders to participate in employment. It also provides examples of good practices in providing this support which can inspire relevant organisations to create further employment opportunities for people with autism. Overall, this report provides a foundational guide for people with autism, their families, employers, policy-makers and anyone else working towards the goal of employment for people with autism.

This report has been produced on the basis of a review of the academic and professional literature on the topic of employment and autism, as well as a questionnaire conducted among Autism-Europe's members (associations for people with autism from across Europe). Some of the examples of good practices in the field of employment for people with autism have been provided on request by Autism-Europe's members and other relevant organisations.



### **ISSUES AND DIFFICULTIES FACED BY PEOPLE WITH AUTISM IN RELATION TO EMPLOYMENT**

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

Each person with autism is different, however they have impairments in three main areas: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour.<sup>1</sup> They can also experience hyper- or hypo- sensitivities to tactile, auditory, and visual stimuli, and have unusual responses to heat and cold and/or pain.



Restocking and tidying the shelves in a supermarket in Spain.



Working in a canteen in Italy.

Due to their impairments, people with autism often experience the following difficulties that hinder their ability to participate effectively in work:<sup>2</sup>

- Social interaction: People with autism may not understand the unwritten social rules that others usually pick up without thinking. For example, they may stand too close to another person or start a conversation on an inappropriate subject. They may appear insensitive, as they have not recognised how someone else is feeling. They may also prefer to spend time alone rather than actively participating in social conversations and events in the workplace. Thus, people with autism can experience difficulties interacting with managers and colleagues, which can hinder their inclusion in the workplace.
- Social communication: Many people with autism have a very literal understanding of language, and can struggle to understand metaphors, idioms, irony and sarcasm. For example an expression like "it's raining cats and dogs" can be taken literally. Thus they can have difficulties in understanding and interpreting instructions and unspoken expectations. People with autism can often appear very blunt, and have difficulty reading facial expression or tone of voice. Some people with autism may have very good language skills but might find it difficult to understand the back and forth nature of conversations, and may talk at length about their own subjects of interest and not appear to be interested in what others are saying. Other people with autism may not be able to speak at all, and may instead communicate using gestures or visual symbols.

- Social imagination: While some people with autism have active imaginations, are very creative, and may be successful musicians, artists and writers, people with autism generally lack social imagination. They may find it difficult to understand and interpret other people's feelings, thoughts and actions. They can also have difficulties to predict what will happen next and to understand the concept of danger. This can also affect the way they prepare for change and plan for the future. They often display difficulties to cope with change and unfamiliar situations.
- Cognitive functioning:<sup>3</sup> Many people with autism have difficulties in completing tasks at work due to problems with planning, attention shifting and working memory. Even those who have an average or above-average level of intelligence may still have difficulties with problem solving and organisation, which can affect their performance at work.

Due to their difficulties, as well as a lack of support and widespread stigma and discrimination, people with autism experience many barriers to gaining and maintaining employment. According to the International Labour Organisation, the proportion of people with disabilities not participating in the labour market is at least twice as high as that of average EU citizens, and the unemployment rate is even higher amongst some specific disability groups, such as those who have autism.<sup>4</sup> There is no consistent international statistical data available for the employment rate of people with autism but various surveys indicate that only a minority are employed. A study in the United Kingdom in 2009 found that only 15 per cent of people with autism are in full-time employment and 9 per cent are in part-time employment. The same study also found that 79 per cent of people with autism who are dependent on financial support from the government say they would like to work, with the right support for their difficulties.<sup>5</sup>



Mechanic's assistant sorting out tools in Spain.

The barriers to employment faced by people with autism start long before a person reaches working age and begins to look for a job. These barriers can be summarised as follows:<sup>6</sup>

Lack of access to all levels of education and vocational training: Many adults with autism have not had consistent access to education that is appropriate for their needs during their childhood and youth. A study in the United Kingdom in 2006 found that one in five children with autism has been excluded from school, many of them more than once. The same study found that over 50 per cent of children with autism are not in the kind of school that their parents believe would best support them.<sup>7</sup> France has been condemned twice by the Council of Europe for failing to provide education to children and young people with autism. In France, the number of children with autism in school decreases significantly at each stage of compulsory schooling: 87 per cent of children with autism attend primary school, 11 per cent attend lower secondary school and 1 per cent attend upper secondary school.8 These statistics reflect the widespread lack of access to primary and secondary education for people with autism across Europe. Research has also demonstrated that many adults on the autism spectrum achieve academic results below their potential.<sup>9</sup> For those adults with autism who have successfully completed secondary school, there are also many barriers to vocational training and higher education. Across Europe, there is a widespread lack of vocational training and higher education options that are suited to the needs of adults with autism. While some adults with autism who have a high level of intelligence do manage to gain a university education, many of them experience significant challenges as a result of their autism, such as difficulties with personal organisation and planning, and high levels of social anxiety. Many do not find adequate support for these difficulties, leading them to leave higher education before graduating. Those who do graduate often do so only to find themselves unprepared for the social and communication demands of the workforce.

- Lack of support for the transition to adult life: Across Europe, there is a serious lack of services to assist adults with autism to make the transition from school to adult life. This transition includes not only gaining vocational training or a higher education, but also developing skills for independent living and social and communication skills for employment that are not taught in mainstream education institutions because people who do not have autism usually learn these skills from context. As a consequence, long-term outcome studies of adults in the United Kingdom, Canada, the United States and Japan have consistently reported low levels of independence and poor employment prospects. Even for individuals who have autism and only require a low level of support, the proportion in work rarely exceeded 30 percent, and the majority of their jobs were unskilled and poorly paid. Research suggests that outcome, in terms of independence and employment, amongst more able individuals with autism is likely to be determined as much by the services to which they have access as adults, as by their own innate abilities.<sup>10</sup> The lack of support for the transition to adult life is even greater among those adults with autism who require higher levels of support.
- Barriers during the recruitment process: Getting a job can be very difficult, given that the usual recruitment processes adopted by employers are not accessible for people with autism. The challenges for a person with autism begin with the job application and interview process, which are challenging given the difficulties they experience in communication and social interaction. Even when people with autism are highly educated, they still tend to get jobs that are below their level of ability. It is also common for adults with autism to have their employment terminated by their employer due to problems with their performance at work related to their difficulties in communication, social interaction and executive functioning.
- Discrimination in relation to employment: This can occur at many different stages of the employment process and can take a multitude of forms. Perhaps the most obvious form of discrimination affecting people with autism is discrimination by potential employers during the recruitment process, which can be very difficult for a job applicant to prove.<sup>11</sup> While a person with autism may face discrimination at work, they may not recognise when they are being discriminated against, and lack understanding of their rights and how to exercise them. A study of legal cases in the United States in which people with disabilities who were employed alleged that they had experienced discrimination from their employers found that people with autism were less likely to make claims about discrimination than people with other disabilities.<sup>12</sup>

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### STRENGTHS OF PEOPLE WITH AUTISM IN RELATION TO EMPLOYMENT

Despite their difficulties in certain areas, people with autism also have a great deal to offer in the labour market and some of the characteristics linked to their disability can sometimes prove to be an asset. While offering support for their difficulties, it is also important to recognise and make full use of their individual strengths. Each person with autism is unique, and many have characteristics<sup>13,14</sup> and an above-average level of skills in specific areas<sup>15</sup> that could help an organisation that employs them to thrive, including:

- High levels of concentration and ability to excel at repetitive tasks: People with autism often find focusing on detailed work rewarding, and can tend to work persistently and without being distracted, paying close attention to detail.<sup>16</sup>
- Reliability, low level of absenteeism and loyalty: People with autism can be very conscientious and committed to their work, often with good levels of punctuality, honesty and integrity. For example, their rate of absenteeism is often lower than that of other employees.<sup>17</sup>
- Detailed factual knowledge, specialist technical skills and interests: The tendency of some people with autism to develop specialist interests can lead them to develop very detailed factual knowledge in that area.<sup>18</sup> They can also develop highly specialist skills, especially in technical fields, which can be very valuable in the workplace, as well as an above-average level of systematisation skills, including understanding of rule-based systems and patterns.<sup>19</sup>
- Excellent record-keeping and memory: People with autism tend to have strong memorisation skills and a tendency to be good at record keeping.
- Problem-solving skills: People with autism tend to prefer logical and structured approaches to their work, and often think in a very visual way. They may enjoy problem-solving and can bring new ideas and take fresh approaches to their jobs.<sup>20</sup>
- Retention: People with autism have a preference for routine and once settled in a job will often stay in that role considerably longer than others.<sup>21</sup>
- Resourcefulness: People with autism may also have had to find ways to overcome challenges and so can be very resourceful.<sup>22</sup>

People with autism can be particularly suited to jobs that most people are not suited to, such as positions that require work of a repetitive nature and positions that are socially isolated due to the nature or location of the work.<sup>23</sup>



### **EMPLOYMENT RIGHTS IN THE INTERNATIONAL, EUROPEAN AND NATIONAL CONTEXTS**

There are instruments in place at international, European and national levels to protect the rights of people with autism in relation to employment.

People with disabilities, including people with autism, have equal rights and are entitled to dignity, equal treatment, independent living and full participation in society. These principles are enshrined in the United Nations Convention on the Rights of Persons with Disabilities which was adopted in December 2006. The Convention does not establish new rights, but restates, reinforces and updates rights contained in other international instruments, and confirms that all such rights apply to persons with disabilities.<sup>24</sup> Among the rights outlined in the Convention, the rights of people with disabilities in relation to employment are detailed in Article 27, which is quoted throughout this report.

The European Union ratified the Convention in 2010. As the European Union and national governments share responsibility for policy in the fields of employment, social affairs and inclusion, the responsibility for implementing these aspects of the Convention is also shared.<sup>25</sup>



Restocking supermarket shelves in Hungary.



Computer-based work in the United Kingdom.

On the part of the European Union, the European Commission makes laws and monitors their implementation in areas like employment rights and coordination of social security schemes; coordinates and monitors national policies; and promotes the sharing of best practices in fields like employment, poverty, social exclusion and pensions.

The European Union also has the power to address discrimination based on sex, race or ethnic origin, religion or belief, disability, age or sexual orientation.<sup>26</sup> Thus, in 2000, the European Union adopted the Employment Equality Framework Directive 2000/78/EC<sup>27</sup> which requires all Member States to adapt and develop national legislation to prohibit direct and indirect discrimination against people with disabilities (among others) in the area of employment and vocational training. The Directive applies, inter alia, to selection criteria and recruitment conditions, vocational guidance, vocational training, employment and working conditions, including pay. Importantly, the Directive states that "reasonable accommodation" shall be provided, which means that employers are to take appropriate measures, where needed, to enable a person with a disability to have access to, participate in, or advance in employment, or to provide training, unless such measures would impose a "disproportionate burden" on the employer. While all European countries now have such legislation in place, the impact of this directive remains limited in practice.28

Autism-Europe considers that the scope of this directive does not provide adequate redress for the discrimination in employment that is commonly faced by people with autism. In addition, under this directive, an employer may simply justify a decision not to hire a person with autism because the training and adaptations required for a person with autism, especially for a person in need of a high level of support, would impose a disproportionate burden. Autism-Europe believes that a directive with a broader scope to address discrimination that people with autism face could be far more effective.<sup>29</sup>

In this vein, a European Union directive to combat discrimination in other fields of life, outside of employment, was proposed in 2008. This directive has since unfortunately been withheld in the policy development process due to lack of consensus among the Members of the Council of the European Union.<sup>30</sup> While such a directive could be a useful instrument to protect the rights of people with autism and prevent discrimination, this is not the only legal and policy issue that people with autism face in relation to employment.

"1. States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realisation of the right to work, including for those who acquire a disability during the course of employment [...]."

"2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour."

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

At the national level, most Member States of the European Union have signed and ratified the United Nations Convention on the Rights of Persons with Disabilities. The degree to which the Convention has been implemented in Member States is diverse at this point in time, especially in relation to Article 27 on employment. In order to meet their obligations for the implementation of the right to employment, many Member States need to review and critically evaluate all other relevant existing national legislation and modify it as appropriate.

Legislation is not enough, however, as even where sound legislation is in place, discrimination against people with autism and other disabilities still occurs and significant barriers to their participation in the workforce continue. Positive measures from governments are also necessary, such as coordinated national or regional strategies to support people with disabilities into employment, funding for programmes to support people with disabilities to gain and maintain employment, financial incentives for employers to hire people with disabilities, financial support for employers to provide reasonable accommodation for people with disabilities and effective implementation of quota systems that require employers to hire a percentage of employees with disabilities.

National and regional employment strategies should be comprehensive and encompass all elements necessary to foster the inclusion of people with disabilities in the labour market, such as habilitation, education, vocational training, guidance, counselling, financial incentives for employers to hire people with disabilities, support programmes and services, support for developing the skills of disability professionals, and promotion of innovative practices. Strategies should also be designed to take into account the diversity of disabilities. In this vein, specific employment strategies for people with autism have already been launched in some countries. It is also necessary for national governments to ensure that people with disabilities benefit from sufficient social protection. This includes access to forms of support that enable them to participate in the workforce. Social welfare systems in Europe often create disincentives for people with disabilities to work, by removing state-provided forms of support such as travel support and medical care once a person begins to work. This approach creates a "benefit trap", in which people with disabilities must either pay individually for, or live without, the forms of support they need. When an individual has to pay for these forms of support individually, it can mean that they spend all of their salary on basic living costs and necessary forms of support, leaving them with little or no additional income for other expenses in life, and therefore, no incentive to work. These systems reinforce the exclusion of people with disabilities from the labour market and must be reformed. Social welfare systems for people with disabilities should make a distinction between basic living support payments and other forms of support such as travel support and medical care. While an individual may lose their basic living support payments when they are employed, there should be no loss of other forms of support. People with disabilities should be able to enter employment and/or return to receiving basic living support payments when necessary without fear of being unfairly penalised.

In order for positive measures adopted by national governments to be effective, it is also necessary to combat stigma and prejudices associated with disability amongst employers by demonstrating the potential of people with disabilities and mobilising local communities in strategies to employ them.<sup>31</sup> In this respect, public authorities have a duty to lead by example, and take an inclusive and anti-discriminatory approach by employing people with autism and other disabilities.

#### "g) Employ persons with disabilities in the public sector;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities



# Addressing the need for employment and support through national legislation and strategies

#### The Autism Act 2009 and the Autism Strategy (England)

The Autism Act 2009 is the first ever disability-specific law in England. It was created to address the lack of support for, and understanding of, people with autism among the relevant authorities in the country.



The British Parliament adopted the Autism Act, the first disability-specific law in England, in 2009.

The Act required the Government to produce a strategy to address the needs of adults with autism, as well as statutory guidance for local councils and local healthcare organisations on how to implement the strategy. Thus, in 2010 the 'Fulfilling and Rewarding Lives' strategy was created to ensure that adults with autism receive the support they need, ranging from assistance at home to support to gain employment.

The priorities of the strategy were:

- improved training of frontline professionals in autism;
- improving access to diagnosis and post-diagnostic support;

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- development of 'local autism teams' to provide assessment and support;
- better planning and commissioning of services, including involving people with autism and their parents or carers in service development;
- leadership structures at national, regional and local levels for service delivery.

Following a review of the strategy in 2014, a new strategy called 'Think Autism' was created. While the obligations and recommendations from the previous strategy still apply, the new strategy focuses on building communities that are more aware of the needs of people with autism and more accessible to them (including employment support services). It also aims to encourage innovative local ideas, services or projects that can benefit people with autism and to improve coordination among service providers. The Government has also allocated £4.5 million in funding which will be used by the Department of Health to implement the new strategy.

More information: www.autism.org.uk

#### **Employment opportunities in public administration**



## The National Autistic Society and the National Archives (United Kingdom)

The National Archives of the United Kingdom now provides training and employment opportunities for adults with autism.

In collaboration with the National Autistic Society, the National Archives has recruited and trained new employees who have autism. Managers have received training to ensure that suitable adjustments are made to create an inclusive working environment and ensure their staff with autism are meeting their workplace potential.

The National Archives also offer work placements to give people with autism the opportunity to gain valuable work experience and develop a range of interpersonal and life skills.



The National Archives building in London, United Kingdom.

A structured work placement provides the opportunity to learn more about what it is like to work in an archive, and to get some practical, hands-on experience of working as part of a team. A typical placement is no more than two weeks in duration, within the Document Services department.

The tasks at the National Archives include:

- withdrawing and returning original documents accurately to and from different locations within the archives;
- using computer systems to log and track document movements accurately;
- working in a customer service environment;
- learning how documents are preserved and cared for;
- learning about the document relocation processes;
- working as an effective member of a team.

More information: www.autism.org.uk/employmentservices



## PATHWAYS TOWARDS EMPLOYMENT

It is clearly established that people with autism have the right to employment. In order to fully enjoy this right, most people with autism require some support to gain and or maintain employment. This section outlines various approaches to, and structures for, providing support for people with autism to overcome the difficulties they face and work effectively in a diverse range of work environments.

# Individualised planning and evolving support throughout the lifetime

Support for a person with autism to participate in employment begins with support for planning their education, training and employment options. As they become adults, many people with autism – even those who have successfully completed high school within the mainstream education system – face a lack of post-school programmes and support services, jeopardising their chances to access employment and be included in society.<sup>32</sup> Long-term transition planning for children with autism is an important element to ensure a person with autism has the best possible chances of reaching their potential in the future.<sup>33</sup>

Planning should include adapting support to meet each individual's needs, based on their motivations and strengths, in order to find the best possible options for employment. A wide range of options could be considered, including structured day-care centres, sheltered employment, supported employment programmes and employment in a mainstream work environment.

To ensure that planning is individualised, the staff in organisations that provide planning services for people with autism to facilitate their transition into employment must have enough flexibility and autonomy within their roles, as well as flexible budget structures, to find options that meet the needs of each individual with autism.<sup>34</sup>

Research evidence shows that having a job does not necessarily lead a person with autism to live a more independent life. Significant challenges beyond just getting a job remain for people with autism to become more independent.<sup>35</sup> In order to foster their participation in society, and in the labour market, an array of other support services (based upon an up-to-date knowledge of autism) must be fully accessible and tailored to the needs of people with autism. People with autism are likely to require assistance in developing a wide range of skills for their personal lives that enable them to be independent and support their ability to work<sup>36</sup>, such as: budgeting, banking, paying bills; personal care and hygiene skills; cleaning, cooking and household maintenance skills; using public transport; time management skills; problem-solving skills; etc.

Just as planning and support should begin long before a person reaches working age, support should also continue during and after employment. It is particularly critical to consider the transition periods in the life of the person. This includes not only the transition from school to further education and employment, but also transitions from one job to another and the transition from work to retirement. Most people with autism require support in various areas of their life, according to their individual needs, and this support should evolve with the changes in their lives, throughout their lifetime.

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# An individualised approach to finding the right jobs for people with autism



#### Salva Vita Foundation (Hungary)

Salva Vita Foundation is the first non-profit organisation in Hungary to provide specialised support to facilitate the inclusion of people with autism in the open labour market.

The foundation launched a specific support programme for people with autism in 2011, after realising that their needs were not accommodated suitably by using existing services designed for people with mental or learning disabilities.

The programme offers a flexible approach to assess the needs of support of individuals with autism and match them with adequate jobs. The level of assistance and accommodation required by each person with autism is assessed by a multi-disciplinary team, via a three-phase process:



Salva Vita Foundation helped a young man whose interests were cleaning and trains to find a job in Budapest cleaning city trams.

- Interview phase: general questions about their desires and needs, their medical and educational history and their interests.
- Comprehensive skills assessment: reading, writing, maths skills, but also social interaction, time management and spacial orientation.
- Trial work experience: assessment of the persons' abilities in the work environment, including their communication and interpersonal skills in different work placements, for a maximum of four hours at a time. This can be repeated if needed.

Matching people with autism with the right job also involves confronting prejudice and stigma against people with autism and creating a network of potential employers. The Foundation raises awareness among employers and trains them to provide tailored support for the needs of the person with autism.

Since its creation, the programme has supported the inclusion of 11 people with autism in the labour market and ten of them are still employed.

#### More information: www.salvavita.hu/en/

# Adapted post-school education and work skills training programmes

Education is a key factor in accessing employment. As already highlighted in this report, children and adults with autism are still often excluded from the education system. It is thus necessary that governments adopt national policies and strategies to ensure access to lifelong education, from preschool facilities to post high-school education, including vocational training. Training for maintaining and improving communication, social and personal skills should also be available to people with autism compensate for their difficulties in these areas.



In training to prepare for work in a warehouse in Hungary.



Preparing meals as a vocational training and therapy activity in Austria.

Some people who have autism are able to succeed in higher education, although they may need some extra support to settle into, or manage, university life. For example, they may require assistance with timetabling and structure, finding their way around university, developing strategies to manage anxiety and support in lectures and laboratory sessions.

For people with autism who cannot attend university, vocational training courses can be an excellent way to develop skills for employment. Vocational education and training offered to people with autism should adopt evidence-based approaches to teaching and learning, and according to individual needs, may also involve adapted educational settings and specially trained teachers. Vocational education for people with autism often takes place within organisations that specialise in working with people who have autism, although in some countries, mainstream education institutions are now offering specific support to enable people with autism to participate and succeed in vocational courses alongside other students.<sup>37</sup>

People with autism should also benefit from training in interpersonal skills for the workplace and work-related daily living skills to compensate for their difficulties. This can include support to learn appropriate communication skills and behaviours for the workplace, such as email etiquette, appropriate topics of conversation in the workplace, asking for help and accepting constructive criticism.<sup>38</sup> While most people learn

these skills from context, these skills are difficult for people with autism to learn, and need to be taught explicitly. They are also likely to need assistance with searching for a job, including preparing a resumé, searching for jobs, completing job applications, developing interview skills, and dressing appropriately for interviews and workplaces.

It should be noted that many adults with autism have received a diagnosis later in life (or haven't received a diagnosis at all), and have not had the same opportunities to develop through education and training as many children who are diagnosed today. Yet, adults with autism are able to continue learning and developing new skills throughout their lifetimes. Employment and training options must be designed to accommodate the needs and skills of adults with autism who are diverse in age, ethnicity, skills and prior educational experiences. Among adults with autism who have been employed, many report that they have spent a limited amount of time in employment in which their needs were not met and their experiences of work have been quite negative. In these cases, programmes to support their return to work and job retention may be required, and should include assessment of individual strengths, skills, interests, career aspirations, challenges and (re)training and support needs. Such programmes should be evidence-based, multidisciplinary and take into account the individual needs of each person with autism.

"d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

#### Turning life around through education and training



#### Specialisterne (Iceland)

Participation in specialised vocational education and training is leading adults with autism in Iceland to turn their lives around.

Specialisterne is an organisation that provides vocational education, training and employment for adults with autism in numerous countries around the world.

In Iceland, the organisation has provided training and found jobs for 40 people with autism over the past three years.

Specialisterne's assistance has helped many individuals with autism turn their lives around, not only developing skills for employment, but also for social interaction.



Specialisterne in Iceland offers vocational training to people with autism in order to help them find employment

For example, a 35 year-old man who came to Specialisterne for training was socially isolated, had poor personal hygiene habits, and his daily routine consisted of sleeping during the day and staying awake all night, always on his computer.

Specialisterne's comprehensive training prioritises the need for individuals with autism to be able to follow a regular schedule before assisting them to find a job.

The man's participation in the training led him to follow a healthier daily routine, to develop better personal hygiene habits, and enabled him to begin socialising in the cafeteria and the gym, as well as to maintain better relationships with members of his family.

More information: www.specialisterne.is

#### Career exploration and gaining work experience

Perhaps even more than other young adults attempting to enter the labour market, people with autism can benefit significantly from introductory experiences in the workforce such as work experience programmes, internships, 'job shadowing' opportunities, apprenticeships, part-time jobs and volunteering. If structured to accommodate the needs of people with autism, these can provide very useful experience in learning and practising the behaviours and communication required in workplaces.<sup>39</sup> These experiences can also provide an opportunity for people with autism to participate in assessing and developing their own abilities, skills and interests in relation to potential jobs before making the transition into the workforce.

It can therefore be useful to provide a person with autism with the opportunity to try a job during a limited period of time in which both the potential employer and employee can determine whether the individual is suited to the position or not.<sup>40</sup> A programme in the United Kingdom called the Job Introduction Scheme (JIS) allows people with disabilities to try out a job to see if it's suitable, with government funding provided to pay the salary of the worker with a disability for the first few weeks.<sup>41</sup>

# Gaining skills through raising awareness and advocating for autism culture

#### Puoltaja online magazine (Finland)



Volunteers working at Puoltaja online magazine.

'Puoltaja' is an online magazine produced in Finland by volunteers on the autistic spectrum; most of them with Asperger's Syndrome.

The Finnish Association for Autism and Asperger's Syndrome came up with the idea to create *Puoltaja* after noticing that many people with autism were actively writing in online forums and social media websites.

Meaning 'advocate' in Finnish, *Puoltaja* is published four times a year and has around 2,000 readers. Its main purpose is to advocate for autism culture, raise awareness about autism among the public and the

mainstream media, and give a voice to the positions and opinions of people with autism. It also aims to challenge some predominant stereotypes about autism.

For the voluntary staff who work as editors, *Puoltaja* provides practical skills that could help them in the labour market.

#### More information: www.puoltaja.fi/

#### "j) Promote the acquisition by persons with disabilities of work experience in the open labour market;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

#### **Networking**

Finding a job is challenging for anyone. For people with autism in particular, building on the personal and professional business contacts of the individual with autism, their family, neighbours, friends and support organisations can be a more effective strategy for finding employment than sending applications for advertised positions in the open labour market and making 'cold calls' to potential employers.<sup>42</sup>

The ability to create meaningful work experience and employment opportunities for an individual with autism through community contacts is likely to be more successful if the individual has built a relationship with people in the local community over time. This allows the individual with autism to develop a level of comfort with others and vice versa. These relationships can for example be built through regular contact with people in local businesses, cafés and recreational facilities.

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# Working hand in hand with local companies to create jobs for people with autism

#### Autismo Andalucia (Spain)

In the south of Spain, Autismo Andalucía works with a wide range of local companies to create jobs that are individually suited to people with autism.

Autismo Andalucía networks extensively with local organisations, from small local businesses to local offices of multinational companies, to create opportunities for the inclusion of people with autism at work.

The programme provides people with autism with individual support, such as specially trained job coaches, to help them develop the skills required for their jobs, and to provide support in communication with their



Technical assistants archiving videotapes in a local organisation.

managers and colleagues. The support is gradually withdrawn when the presence of the job coach is no longer necessary and can be replaced by natural supports, such as colleagues who can understand and support the needs of the individuals with autism within the workplace.

The programme – the first of its kind in the south of Spain – was launched in 2006. Since then, it has supported 120 people with autism, aged between 17 and 50 years, and mostly with very low levels of education, into employment. The programme has contributed to the creation of 100 work contracts and 36 professional training experiences in companies within the open labour market of the region. The jobs are created according to individual skills and interests including kitchen assistants in restaurants, shop assistants, laundry workers and cleaners.

The positive role that these companies play in including people with autism in society is acknowledged through awarding them for their action and media campaigns to draw attention to the positive examples they set for others. This acknowledgement contributes to raising awareness among new companies that can, in turn, hire people with autism.

#### More information: www.autismoandalucia.org

# Intermediaries and specialist support to create pathways into work

Even when a person with autism has completed education and/or training programmes and identified a career that would suit their skills and abilities, in most cases, support is still required to assist the individual to gain and maintain employment.

Due to the social and communication difficulties that people with autism face (to varying degrees), most still find that the social and communication skills required to gain and maintain a job are a significant barrier. To overcome these barriers, support from intermediaries such as individuals or organisations providing specialist services in employment for people with autism can be very effective.

Intermediaries provide an interface between the person with autism and the employer or potential employers with the aim to bridge gaps in communication and understanding. Intermediary support for people with autism to gain and maintain employment is a relatively recent phenomenon and various approaches to providing this support have emerged across Europe and around the world, including:

- organisations specialising in employment support for people with autism;
- staff within general employment support services who specialise in working with people with autism;
- staff within autism organisations who specialise in supporting people with autism to gain and maintain employment.

A common approach to supporting people with autism to gain and maintain employment is to appoint 'job coaches' whose role is to ensure that a job seeker or employee with autism receives the support they need during most or all stages of the employment process, from recruitment to retirement or termination of employment. As described above, job coaches can be employed by companies, employment support services or autism organisations. They are specially trained in understanding the common and individual needs of people with autism in relation to employment and they provide significant support based on their own skills and knowledge as well as drawing upon other resources to support people with autism when required.

While different approaches can be effective in different contexts, research evidence suggests that an interdisciplinary approach, in which a team of professionals and relevant people are involved in the process of assisting a person with autism to gain and maintain employment, can be very effective. Such a team can include job coaches, managers, occupational therapists, special educators, psychologists, family members and others.<sup>43</sup> Research evidence also suggests that specialist employment support services for people with autism can lead to better employment outcomes than more general employment support services.<sup>44</sup>

"e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;"

-Article 27, United Nations Convention on the Rights of Persons with Disabilities

#### Assessment and monitoring

A key aspect to consider when supporting an individual with autism to find employment is to assess whether the potential position is a good job match. It is imperative that the job corresponds to the interests, motivations and strengths of the person.

However, it should not be considered as essential that the skills of the person perfectly match the job. Indeed, people with autism can acquire new skills throughout their lives. Training and adequate support can bridge the gap between the requirements of a job and an individual's existing skills.

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# Capacity building among those who support people with autism at work



In the United Kingdom, there are an estimated 700,000 people with autism and a wide range of organisations that exist to support them across the country. There is also an increasing number of employers who are hiring people with autism.

With so many people involved in this growing area of work, the National Autistic Society has developed an efficient way to help employers, intermediaries and other autism support organisations to develop productive working relationships with people who have autism.



Working together at the National Autistic Society's Employment, Training and Consultancy Service.

The National Autistic Society's Employment Training and Consultancy Service utilises a capacity building approach, providing customised training to managers and staff of companies, employment services and autism organisations. The training aims to increase their skills and knowledge in working with people who have autism, covering topics such as:

- autism awareness;
- recruitment and management of employees with autism;
- engagement with employers to secure work experience placements and jobs;
- identifying reasonable adjustments for people with autism;
- communication strategies;
- supporting people with autism to talk to managers and or colleagues about their disability;
- understanding equality legislation;
- mentoring people with autism at work;
- relevant funding to support individuals in the workplace.

The service also takes a personalised approach to working with individuals with autism to ensure that their needs and abilities are taken into account in their work situations to ensure their jobs are sustainable.

By assisting relevant organisations through high quality training and consultancy services, the National Autistic Society's approach to employment builds capacity among organisations all over the country to work effectively with people who have autism.

The service employs seven staff members and over the past year they have trained over 700 people on understanding autism in the workplace.

#### More information: www.autism.org.uk/supportedemployment

To define the level of accommodation required for the position, the assessment should be comprehensive and take into consideration the specific demands of the job, notably the social interaction skills and behavioural skills required, as well as the general work environment, including the sensory environment.

The potential employers and co-workers should be fully involved in the assessment process. The individual's level of awareness of their own strengths and challenges and their ability to advocate for their own needs should also be considered.<sup>45</sup> If necessary the family, friends or support staff of the person should also be consulted. The assessment should be followed by an ongoing process of monitoring that examines how a person with autism performs in response to various supports and their evolution at work over time.<sup>46</sup>

"a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

# Making the recruitment process accessible for people with autism

In recognition of the fact that people with autism have inherent difficulties in communication and social interaction, support measures are required to assist them to participate in processes such as recruitment interviews and performance reviews.

Simple adjustments at the recruitment stage, such as those outlined below, can make the process of applying for jobs much more accessible for people with autism:<sup>47</sup>

- Job advertisements, job descriptions and person specifications: The key skills needed for a job should be carefully considered and indicated in a clearly worded, jargon-free advertisement, job description and person specification. If excellent communication skills are not necessary for the position, this could be omitted, as it may unnecessarily deter someone with autism from applying.
- Application forms: A section can be added to the job application form where candidates with autism are asked to provide information about any adjustments they may require during the recruitment process and in the workplace to help overcome potential barriers or disadvantages.
- Interviews: Interviews can be especially stressful for people with autism. Difficulties with communication, sensory issues and meeting someone new in an unfamiliar place all present a challenge. The interviewees should be informed in advance about the people who will be on the interview panel (their names and job titles), exactly where the interview will be held and what they can expect to happen during the interview itself. Interviewees should be asked whether they require any adjustments to the interview room, such as changes in the lighting or seating arrangement.

Below are some key pointers for the interview:48

Allowing a person with autism to prepare a set talk in advance, or to view the interview questions in advance before an interview could be useful.<sup>49</sup>

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- A concise interview, asking clear and direct questions, asking for concrete examples, together with a work trial or test may be a good way to test a potential employee's skills and suitability for the job.
- Idioms and abstract language should be avoided, as many people with autism interpret language literally.
- Hypothetical or abstract questions, such as "Where do you see yourself in ten years' time?" can be very difficult for people with autism to answer, as they may find it impossible to make future projections.
- Open-ended questions are also problematic, as a person with autism may find it difficult to determine what, and how much, to say about their experience.
- The candidate with autism could be permitted to be accompanied by someone who can rephrase questions to make them easier to understand.
- Candidates may also benefit from extra time to complete written tests, which should be comprised of short and concise questions.
- Candidates could also benefit from the opportunity to show examples of their previous work or to demonstrate their practical skills.

#### Support at work

Ongoing support is usually required to help a person with autism maintain a job. The type and level of support required will depend on the person's individual needs, but could include the following measures:

- Job design: Adjusting the job description and responsibilities according to the abilities and strengths of the employee with autism and or reassigning tasks between employees can be a useful way to ensure that an employee with autism can function to the best of their abilities in a specific job. Employers reassign tasks among employees according to individual strengths and weaknesses at other times as well, so this is not anything unusual. A high degree of structure, predictability and routine can help the person with autism perform in the position, though this does not necessarily mean that the role should be tedious or boring.<sup>50</sup>
- Working hours: People with autism may find full-time work too overwhelming at the beginning of their employment. Commencing employment on a part-time basis and gradually increasing hours of work could be an effective way to support an employee with autism to adjust to their new role and environment.<sup>51</sup> Also, unstructured, non-defined time (breaks, for instance) is usually difficult. Reducing unstructured time or providing meaningful activities for the person with autism during these times can be helpful.
- Workplace communication: As people with autism have difficulties in communication and social interaction, an important step for employers in adapting a workplace is to identify, understand and articulate the workplace's normative behaviour and communication practices, and to explain these to employees with autism and or adapt practices to accommodate employees with autism.<sup>52</sup> Allowing a person with autism enough time to respond to verbal



Developing woodwork skills with personalised assistance in Austria.



Working in small teams to avoid stress in France.



Working in hospitality in the United Kingdom.

communication can also assist them to communicate more effectively. In addition, modifiable scripts may be used to teach and assist a person with autism how to communicate effectively in various situations.<sup>53</sup> Advice regarding the use of clear and direct language (as outlined in the section on conducting job interviews) of course also applies when the person has been hired.

- Work environment: This should be calm, structured, consistent, dependable, reliable, supportive, accommodating, comfortable and predictable. Adapting the work environment can include adjustments to the noise level, lighting, degree of crowding and ease of navigation in the workspace, as well as the number of interruptions during work time.<sup>54</sup>
- Raising awareness in the workplace: It can be particularly beneficial to organise general and specific autism awareness training for other staff who work with the employee(s) with autism to inform them about the challenges experienced by the employee(s) with autism and how to support them. It should of course be undertaken with the consent of the person with autism. More information on this topic is provided in the section of this report on managing a person with autism.
- Natural supports/mentoring: Identify additional support people such as supervisors, co-workers, employment specialists, family members or friends who can assist the person with autism to perform in their role in various ways, such as assistance with transportation to and from work, and explaining and reminding them about work tasks. A staff member can act as a mentor, through helping them with any issues that arise and advocating on their behalf if necessary. This can be a person who develops their skills in working with the person with autism to a higher level than other colleagues and can provide supports such as 'translating' communications for the person with autism into language that is easier to understand.<sup>55</sup> This can be a very cost-effective strategy for support that also promotes inclusion in the workplace. If natural supports are the main form of ongoing support offered to a person with autism, it is essential to ensure that the colleagues involved are aware of and agree to being in this role, have an understanding of the person with autism's needs and how they can assist them, and can also find support for being in this role when they need it. Any potential conflicts of interest between the person with autism and their natural supports should also be acknowledged and avoided.

"b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

- External support organisations: Organisations that offer job mentoring, coaching, and general and specific job assistance to people with autism can be called upon to provide assistance. Some good practices in supported employment can include ensuring that the support workers are available (for example via mobile phone) for after-hours support calls and identifying and training a secondary support person for when the person with autism's main supporter is unavailable.<sup>56</sup>
- Assistive technology: Tools such as Personal Digital Assistants (PDAs), email programs and other software programs can offer daily scheduling and task management functions that can assist a person with autism to manage their time and meet deadlines at work. Alternative forms of communication can also assist an employee with autism, such as email, instant messaging or software programs program to communicate through pictograms. Earplugs, noise cancelling headphones or white noise machines can assist a person with autism to block out other sounds that would otherwise be distracting.<sup>57</sup>
- Organisational assistance: The use of instruction sheets, checklists, labels and notebooks may also be beneficial for a person with autism to maintain their schedule and meet deadlines at work.<sup>58</sup>
- Stress and anxiety management: Taking regular breaks or having a designated place to go or activity for an employee with autism to do in order to avoid becoming overwhelmed when experiencing stress or anxiety in the workplace can also be a useful coping strategy.<sup>59</sup> An individual with autism may benefit from developing relaxation, emotion and anxiety management strategies that can be applied within the workplace.<sup>60</sup>



Making gifts in the Czech Republic.

- Consistency and flexibility of support: The support needs of employees with autism are likely to change over time. At times of organisational change (new staff, new managers, moving to a new work location, during periods of stress, deadlines, etc) their support needs are likely to be higher. Managers and intermediary support organisations must be prepared and flexible enough to quickly accommodate these changing needs.<sup>61</sup> It is necessary to ensure that support structures in place to accommodate people with autism do not break down during periods of high workload, deadlines, stress and when the organisation as a whole is under pressure to meet core organisational objectives.<sup>62</sup>
- Occupational health and safety: With regards to occupational health and safety, people with autism may require additional guidance in ensuring that they can understand and follow safety procedures.

"i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;"

"k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities."

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

# Working with an external organisation to integrate people with autism into the company

#### L'Oréal (Italy)

Since 2011, L'Oréal in Italy has been working on a project to provide training and employment opportunities for people with autism.

The project aims to bring adults with autism, aged 30 to 35 years, into the company for training with the possibility of employment.

L'Oréal is working with Fondazione TEDA (an autism association) to identify people with autism who could participate in the project.

The activities proposed to people with autism include administrative tasks such as working with databases, updating files, data entry and archiving, as well as packaging cosmetics, quality checking, security and other tasks. The company aims to ensure that the activities match the person's interests and abilities, and that the person with autism will be able to complete the tasks according to the company's standards.

As part of the project, the company has created training for employees with autism, managers and other staff, and specific staff members have been designated to act as coaches for trainees and employees with autism. People with autism also receive individual support from external coaches (one external coach is available for every three employees with autism).

In the beginning, people with autism work part time to avoid exhaustion and the level of support they receive is progressively reduced as each person becomes more competent in their job.

Sensory issues in the work environment are also considered according to individual needs, and visual communication methods are used to communicate concepts and procedures clearly to people with autism.

L'Oréal's other employees also receive training and information materials on autism and the project.

L'Oréal has an internal policy to ensure they employ people with disabilities in at least two per cent of positions within the company.

More information: www.loreal.com/diversities/our-main-actions/italy.aspx

#### Managing someone with autism

Adequate support and direction from managers is essential for successful employment, for both the employee with autism and the employer.

Effective communication is very important. The employee with autism should be given clear instructions about exactly how to carry out each task, from start to finish. It is advisable to give written and visual instructions, as well as oral instructions, and to be clear about what is expected from the employee (and any consequences of expectations not being met). Managers should always

32 AUTISM AND WORK check that the person with autism has understood their instructions. Since people with autism are often perfectionists, it is advisable to explain what is seen as a successful achievement in order to avoid frustrations. In addition to explaining tasks and achievements, it is also useful for managers to explain policies and/or expectations about staff conduct and workplace behaviour. Managers should also explain any changes in the routine in advance, and slowly introduce new interactions and environments that might present challenges.

When employing people with autism, like employing anyone else, there will of course always be some difficulties at work that must be resolved. These problems could involve time keeping, concentration, coping with more than one task, low productivity, communication difficulties, anxiety, and difficulties coping with change, socially inappropriate behaviours, poor hygiene and other issues. The active involvement of the manager and any relevant colleagues in resolving these issues is crucial. Methods of resolving these problems can include conducting autism awareness training, increasing understanding of the specific difficulties of the person with autism among the other staff and adapting workplace procedures to suit the person's abilities.63 Holding regular one-toone meetings to provide feedback to a person with autism can be a useful way of assessing and improving his or her work, conduct and inclusion in the team.



An IT consultant at work with the founder of German company, Auticon.



Working in a warehouse in Hungary.

Difficulties at work are not only a result of the internal difficulties of a person with autism. Issues of bullying and harassment at work are a commonly reported problem faced by people with autism. Taking action to prevent bullying and harassment is an ideal way to handle this issue. This can begin with managers and colleagues gaining an understanding of autism and the vulnerability of employees with autism in relation to bullying and harassment. Ensuring that managers and colleagues have an understanding of the specific challenges and/or behaviours of each employee with autism, and how best to interact with them, will foster a supportive environment. Encouraging staff to seek help from managers or relevant colleagues when they encounter a difficulty with a person with autism and to continuously engage in further understanding of the person with autism, can help to encourage respect and avoid frustration among other staff. When seeking redress of grievances, people with autism may need support in understanding their rights, communicating their grievances and participating in processes to resolve them. Adults with autism often remark that their concerns are not taken seriously enough by those who are in a position to help them address these concerns. It is also imperative that those responsible for handling grievances at work have an awareness of the employee with autism's specific challenges and take these into account during processes for handling their grievances.

When opportunities arise for career advancement, individuals with autism may require additional encouragement and support. This may include support in discussions and negotiations over new roles and responsibilities, as well as reasonable accommodation of their needs in the transition to a new role. Due to the nature of autism, many individuals on the spectrum prefer to avoid changes

in their routine and/or their physical environment, as these can cause significant stress. While this should be respected, opportunities for career advancement should not be avoided on this basis. Rather, appropriate support should be offered in the processes related to career advancement.

Managers and staff who act as mentors or job coaches, or provide other forms of support for people with autism in the workplace should also receive support in their roles. This support can include training, external support organisations from whom they can seek guidance and recognition for their work.

"c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

#### Self-advocacy skills at work

While support is often required by people with autism to gain and maintain employment, self-advocacy skills are also necessary. People with autism should be provided with training to develop skills to advocate for themselves and their own needs at work, wherever possible.

Ideally, self-advocacy skills should be taught as early in life as possible. The earlier that an individual with autism starts to learn self-advocacy skills, the more practice and skills they can gain for



Computer software testers at work in Belgium.

Making coffee and assisting teachers at a school in Denmark.

their own empowerment throughout the rest of their life.

People with autism have diverse capacities for self-advocacy, however all people with autism should be given the opportunity to develop self-advocacy skills to the extent possible within their capabilities.

Self-advocacy begins with self-awareness. When an individual has a better understanding of their own condition, challenges and their own needs for support and reasonable accommodation, the more likely they are to be able to express these needs.

Self-advocacy at work for people with autism can include:64

- knowing one's own rights and responsibilities;
- explaining one's own needs and/or disability through the use of words, pictures or gestures;
- where possible, identifying obstacles and difficulties that arise;
- asking for assistance when needed;
- speaking for oneself (rather than someone else speaking for them);
- using resources and supports that are available;
- negotiating with others;

34 AUTISM AND WORK deciding whether (and to which extent), when and to whom one's diagnosis of autism could be disclosed.

People with autism need to receive adapted information and/or training on understanding their rights at work, recognising violations of their rights and developing their skills in self-advocacy.<sup>65</sup> People with autism may also need support in exercising their trade union rights, such as assistance in understanding their rights in specific circumstances and participating in processes related to labour rights and trade union membership.

#### Peer support groups and professional networks

While individual support is necessary to enable each person to gain and maintain employment, support from a peer group may also be beneficial.

Many adults with autism experience social isolation and a lack of friendships and relationships with other adults to whom they can relate. Employment can certainly help to overcome this isolation, yet in can also reinforce a sense of isolation when a person with autism regularly feels unable to participate in social and other activities at work in the same way as their colleagues.

Supported discussion groups for adults with autism can provide a regular opportunity to share experiences, concerns and strategies to overcome difficulties at work.<sup>66</sup> If supported by a trained professional, such groups can also be an opportunity for group counselling and professional development.

For job trainers, mentors, managers and colleagues who support someone with autism at work, peer support networks can also be beneficial. Inclusion of people with autism at work is an evolving field of knowledge and such groups can be an opportunity for professional development.<sup>67</sup>

An example of such a group has emerged at the international level, when a group of 19 representatives from organisations around the world that employ people with autism met in Belgium recently and formed a network. Their network aims to share knowledge and provide a platform for networking among business professionals involved in the employment of people with autism.



IT consultants at work in Germany.



Making leather accessories in Spain.

#### A diversity of approaches for a diversity of needs

This section outlines some of the emerging trends in approaches to, and structures for, the employment of people with autism, highlighting the circumstances in which they can be most effective.

#### Supported employment

Employment in the open labour market for people with autism usually requires the provision of various forms of support, as outlined in earlier sections of this report. Despite the diverse needs of people with autism, all forms of supported employment could be considered to have three crucial elements: paid employment, an integrated work setting and ongoing support.<sup>68</sup> Several researchers have made some further categorical distinctions between some of the most common approaches as outlined below. These can be useful to consider when identifying which structures and supports could be most appropriate for specific individuals and within specific circumstances.<sup>69,70</sup>

#### Individual placement in a mainstream workplace



Working as a cleaner at McDonald's in Spain.

This approach entails an individual with autism being supported by an intermediary (such as a job coach who works for an external organisation that assists people with autism in employment) to gain employment in a mainstream workplace through the open labour market. The employee receives ongoing individual assistance from the intermediary to develop skills to function well in their role and to establish support structures within the work environment. Once the person with autism is equipped to perform independently in their role, the job coach's support is reduced to periodic consultations or telephone support to ensure that the indivi-

dual with autism is supported to maintain their job. While this approach aims for the individual to be as independent as possible within their role, support is only reduced to a minimum, never removed completely. This approach is appropriate for individuals with autism who have the capacity to work within a mainstream workplace with a limited amount of support.<sup>71</sup>

#### Individual support in multinational contexts

Specialisterne & SAP (Multiple countries)



Staff with autism at SAP in India receive individual support.

Danish organisation, Specialisterne, takes multiple approaches to inclusion and support for people with autism in workplaces around the globe.

Founded in 2004 by the father of a young man with autism, Specialisterne is a pioneer in employment for people with autism and has a grand vision: to enable the creation of one million jobs around the world for people with autism.

36 AUTISM AND WORK
The organisation is now operating in 12 countries around the world and has already assisted several hundred people with autism to gain jobs, including the majority of its own staff.

Specialisterne provides training to adults with autism in all aspects of employment, from vocational skills to social skills. Working with each person individually, specially trained staff identify their strengths, interests and preferences in relation to employment as well as their needs for support, guidance and workplace adjustments.

After successfully completing the training, candidates are matched with jobs in the IT field, such as software testing, programming and data entry. Most positions for people with autism are created within Specialisterne, while others are within corporate partner companies.

Specialisterne has worked with companies including Nokia, Deloitte, Cisco, Microsoft and Oracle and is currently working with multinational software company, SAP, to create jobs for people with autism.

Specialisterne recruits and trains candidates for jobs at SAP, and so far, employees with autism have been hired by SAP in Germany, Ireland and India in permanent positions in which they work on software testing and similar tasks.

At SAP, every employee with autism is supported first by autism experts from Specialisterne, as well as by a 'buddy' within his or her team at SAP. Later, specifically trained SAP staff will serve as job coaches in case of difficulties.

Training is provided to managers and colleagues to assist them to interact with, and support, colleagues with autism at work.

Based on the success of the programme so far, SAP has decided to increase the proportion of its employees with autism to around one per cent by 2020.

#### More information: www.specialisterne.com www.sap-tv.com/video/#/13436/autism-at-work

#### An autism-specific work group

This approach involves a small group of people with autism working together with a job coach on an ongoing basis. The employees who have autism are initially provided with training in a group setting that is tailored to their needs. The employees with autism may work independently or together as a group on specific tasks, with the job coach providing ongoing support to them, as required. An autism-specific work group may exist within in a mainstream workplace, enabling employees with autism to interact with 'neurotypical' colleagues (those who don't have autism), but at the same time bringing the employees with autism together due to their specific roles and or their common need for support. The group may be located within a larger office, or it may be a mobile group that works on location-based projects, such as landscaping, grounds keeping or cleaning. This approach allows for a higher level of supervision and support for the employees with autism as the job coach is always nearby.<sup>72</sup> Autism-specific work groups can be an effective structure for individuals who require ongoing support to perform well in a workplace, and in the case of a mobile work group, for those who can handle regular changes in the work location and environment.<sup>73</sup>



### Mobile work group testing access gates in metro stations

Passwerk (Belgium)



Passwerk employees on location, testing access gates in metro stations

A Belgian company, called Passwerk, employs 40 people with autism in software testing and quality assurance projects, both in the office and on location-based projects.

The company was created in 2008, designed around the strengths and needs of people with autism. Passwerk employs one job coach for every eight employees with autism. The job coaches work closely with the employees with autism, providing ongoing training and support tailored to each employee's individual needs.

While most of Passwerk's work is conducted in their office in Antwerp, some projects involve a mobile crew of workers going out to work on location-based projects together.

For example, in 2011, four Passwerk staff members completed a project for the Brussels department of public transport testing software and electronic chips for the access gates in metro stations around Brussels.

Passwerk's staff who have autism are recruited at first to participate in technical and social skills training and assessment. Those who succeed in the initial training period are employed by Passwerk and provided with additional training from professionals experienced in software testing. While no previous experience or formal qualifications are required, Passwerk employees have ordinary to high levels of intellectual ability.

The company has shareholders who receive limited dividends and the rest of the profits are used to raise awareness of the positive qualities of people with autism and or to fund other projects to benefit people with autism.

#### More information: www.passwerk.be

#### Integration within a small business

Under this approach, a small number of employees with autism work alongside neurotypical colleagues within a small business setting. The needs of employees with autism are incorporated into the business' processes and may even be the reason for starting the business in the first place. An intermediary organisation may be involved, or may have even initiated businesses adopting this approach. In any case, the management of the business usually has a sound knowledge of the support needs of people with autism and how to work cooperatively with employees with autism. The small and personal nature of such organisations allows for much supervision and support for employees with autism. It can also help them to feel at ease among supportive managers and colleagues who know and understand them, truly increasing their social inclusion.<sup>74</sup> This approach can be suited to a wide range of businesses (for example, baking, commercial kitchens, printing, garden

shops or greenhouses) and can also be appropriate for a wide range of individuals with autism. As the business is small, the suitability of this approach is very much determined by the individual business' purpose, work environment and staff.

# Small business created out of the passion and skills of (

### **Green Bridge Growers (United States)**

Green Bridge Growers, a small business in the United States was founded to create a job for a young man with autism who has a passion for, and skills in, organic farming.

After graduating from college, Chris Tidmarsh gained a job as an environmental researcher, but the social challenges of being in a traditional job were very hard for him. Despite his best efforts at self-advocacy, he lost his job after a few months.

Realising that unemployment was very common among adults with autism – even those who have college degrees – Chris' mother, Jan Pilarski, began to search for solutions.

After two years of research, Chris and Jan founded Green Bridge Growers; a small business growing organic vegetables using a method called aquaponics where fish and vegetables grow in harmony.



The 'aquaponics' method of farming in which fish and vegetables grow together.

They found that aquaponics was a great match not only for Chris' skills, but for other adults with autism. The farming method requires precision and attention to detail as well as routine.

The business employed Chris and others on the autism spectrum to produce organic vegetables for local markets.

Following the success of its work, the business is now taking its next step: creating commercial aquaponic greenhouses.

The growth of the business has been partially funded by a crowdfunding campaign conducted online to raise funds.

Each greenhouse that Green Bridge Growers builds creates five jobs for young adults with autism and can produce 45,000 pounds of vegetables annually.

More information: www.greenbridgegrowers.org

These are just a few of the approaches to, and structures for, supported employment for people with autism that are emerging around Europe and across the world. Of course, there is an endless number of different possibilities, and most initiatives to employ people with autism do not follow any model precisely and are in reality more often structured according to some combination of the above approaches.

The supported employment approaches to employment in which intermediaries assist people with autism to gain and maintain jobs do, however, have one thing in common when compared to other approaches: research evidence demonstrates many positive outcomes for people with autism who are in supported employment.

Several studies have found that supported approaches to employment for people with autism have proved very effective in assisting them to gain and maintain jobs that are appropriate to their skills and abilities.<sup>75,76</sup>

Research has also indicated that the more specialised the employment support is, the better the outcomes for people with autism are likely to be. A study in the United Kingdom in 1997 compared the employment outcomes for clients of an early supported employment scheme designed specifically for people with autism with the employment outcomes for clients of a closely matched control group who had access only to generic disability employment services. The study found that the supported employment scheme resulted in significantly higher rates of employment amongst its clients than the control group. Even more important was the finding that the types of jobs found (predominantly in administrative or computing work) were far more appropriate to clients' intellectual and educational levels than was the case in the control group.<sup>77</sup> This was mostly due to the fact that staff in generic employment support services for people with disabilities had neither sufficient knowledge of the needs of people with autism, nor the skills and resources to assist them with these needs.<sup>78</sup>

Additional, non-employment related, positive outcomes for people with autism in supported employment have also been reported. A study in the United Kingdom and Spain in 2007 found that supported employment improved cognitive performance among adults with autism. The study compared the results of cognitive tests that measured executive functioning on non-work related tasks between a group of people with autism who were in supported employment and a group of people with autism who were unemployed. The study found that the group who were in supported employment achieved higher test scores for memory, strategy, planning and problem solving tasks after being employed for around 30 months, while the unemployed group's test results showed no change over time.<sup>79</sup>

Research has demonstrated that among the diverse range of people with autism, those who are in need of a medium to low level of support can benefit the most from supported employment.<sup>80</sup> Several studies also indicate that the outcomes of supported employment programmes appear to be superior to sheltered workshops or other day service options, in terms of financial gains, wider social integration, increased worker satisfaction and higher self-esteem.<sup>81,82</sup>

"h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

# Research evidence backs the supported approach to employment



### The Prospects initiative (United Kingdom)

Research evidence from an employment initiative in the United Kingdom found that people with autism who received specialised support were 2.5 times more likely to gain and maintain appropriate and satisfying jobs than those who received non-specialised support.

A two-year pilot study <sup>83</sup> of the 'Prospects' initiative compared the employment outcomes for two groups of people with autism: one group who received specialised support designed to meet the specific needs of adults with autism from the Prospects initiative and another group who received support from a generic disability support scheme.



Sorting the daily mail in Glasgow, Scotland, as part of the Prospects initiative.

The study found that 63 per cent of the group who received specialised support were able to gain jobs that were suited to their intellectual abilities and education levels, while only 25 per cent of the group who received non-specialised support were able to find such suitable jobs.

Following this success, the initiative was expanded to several locations in the United Kingdom. A follow-up study<sup>84</sup> conducted on the initiative over eight years found that the overall proportion of participants in employment had risen to 67 per cent and the majority of jobs they had attained were permanent contracts. The average salaries they received had also risen significantly since the beginning of the initiative. Most of the jobs they had attained were professional, technical or administrative in nature, with some participants of lower intellectual ability or with more severe social or language impairments also taking up other roles that were appropriate to their level of ability. Satisfaction with the initiative among all participants was high.

The follow-up study also found that managers of employees with autism also found the support provided as part of the Prospects initiative to be a very important factor in the employees' success in their roles. Almost all of the managers felt that the initiative had supported them well to resolve any issues that arose and felt that they had personally gained something from working with employees who have autism. Some of their comments included: "It has increased my ability as a manager in general"; "I often apply many of the techniques taught to me by the Prospects employment consultant to the rest of my team"; "I feel it is quite an accomplishment and I'd love to do it again"; "The employment consultant designed a manual for the client on how to do tasks. We have now adapted that manual and use it for all our new starters."

Prospects was an initiative of the National Autistic Society in the United Kingdom, funded by the United Kingdom's Department of Work and Pensions.

### Sheltered workplaces and day activity centres

Sheltered workshops are certainly not a new concept, and they have quite justifiably been the subject of much controversy over recent decades. In some circumstances, however, these remain an appropriate structure for employment of people with autism who are in need of a high level of support.

The term 'sheltered workshop' generally refers to an organisation or environment that employs people with disabilities separately from others.<sup>85</sup> These workshops usually involve people with disabilities working in manual labour jobs. They can take various forms, such as day care centres where people with disabilities participate in occupational therapy programs that involve producing goods and services for non-profit purposes, or where people with disabilities participate in employment activities from which they receive an income.



Developing skills in the Czech Republic.



Taking care of the cattle on a farm in Italy.



Developing woodwork skills in Austria.

Criticisms of sheltered workshops have mainly centred around the segregation and exploitation of people with disabilities and the denial of their rights that has taken place in some of these workshops. For example, workshops in which people with disabilities work in jobs that are below their level of skill, for pay that is below minimum wage, for organisations that profit substantially from exploiting their labour and offer them little or no opportunity to develop their skills for the open labour market.<sup>86</sup> The people with autism who work in these sheltered workshops have often been those who have been institutionalised and their participation in sheltered workshops has not been a result of the free choice of the individual or their family members.<sup>87</sup> Clearly, these practices cannot, under any circumstances, be considered acceptable.

When considering the employment options that can be appropriate for the diverse spectrum of people with autism, it is necessary to consider the principles of the United Nations Convention on the Rights of Persons with Disabilities carefully.

Article 27 of the Convention states that people with disabilities have "the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities." While this Article that deals specifically with employment certainly emphasises the right to employment in the open labour market, which is important for the majority of people with disabilities, it should not be interpreted in a way that precludes sheltered employment as an alternative for those who cannot, or choose not to, work in the open labour market for valid reasons. Article 27 of the United Nations Convention on the Rights of Persons with Disabilities must be understood in the context of the whole Convention which also emphasises "Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity" (Article 3.d), "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices" (Article 3.a) and states that "Nothing in the present Convention shall affect any provisions which are more conducive to the realisation of the rights of persons with disabilities." (Article 4).

# Ensuring a minimum income for people with autism in an adapted work environment



### **ESAT Les Colombages (France)**

ESAT Les Colombages, a sheltered employment service in France, provides paid jobs for adults with autism in sheltered working environments that meet their needs.

The organisation runs five workshops in which employees with autism produce goods and services. These are sold in the open market or through the organisation's retail store, which also employs people with autism.



Furniture restoration at ESAT Les Colombages.

- The workshops include:
- wood furniture restoration;
- packaging sorting, mailing and similar tasks;
- green spaces mowing lawns, pruning hedges and shrubs;
- production of frames for art, advertising and exhibitions;
- catering preparing meals to be consumed within ESAT Les Colombages and related services for people with autism.

Each employee receives a salary and continuously develops practical skills in the various workshops, according to their abilities and choices.

Each employee is paid on an equal basis with others, and their salaries are partially subsidised by funding from the state to ensure a minimum income for people with disabilities.

The employees benefit from work conditions that are adapted to their needs, such as working in small teams and taking breaks as often as necessary to avoid stress.

While ESAT Les Colombages offers its services on the open market, its focus is not on profitability. The well-being of the employees with autism is the highest priority, as supervisors pay close attention to each individual's needs and assist them to develop social skills as well as work skills, and employees are not punished if they are not highly productive.

ESAT Les Colombages is managed by AFG-Autisme (Association française de gestion de services et établissements pour personnes autistes), a French organisation that was created by parents of people with autism.

#### More information: www.afg-web.fr



Working in a greenhouse in France.

The lifelong difficulties experienced by some people with autism, especially those in need of a high level of support, can lead them to face extreme difficulties in trying to participate in employment in the open labour market, no matter how much education, training and exposure to the work situation that they have had, and even when reasonable accommodation is provided.

In the open labour market, the needs of the organisation determine the work to be done, the availability of jobs and the specific roles available for individuals to fulfil. Reasonable accommodation can certainly be made for people with disabilities in these circumstances, yet for some adults with autism who are in need of a very high level of support, it is not reasonable to expect that most employers could meet their very high level of support needs. For many of these adults with autism who are in need of a very high level of support, it is also likely that work environments in the open labour market environment will continue to be too challenging because they require more support than can reasonably be provided. To subject a person to situations that are highly stressful or even completely overwhelming for them, without adequate support, when this can be avoided, can be dangerous for the individual and can also be regarded as an abusive practice.

For adults with autism who are in need of a high level of support, sheltered workshops can provide an alternative in which their needs can not only be accommodated, they are the top priority of the organisation. Sheltered workshops can offer adults with autism a safe, calm, stable and predictable environment in which support is provided at all times according to each individual's high level needs and activities are arranged according to individual abilities. They can provide education and practical training on-the-job, using methods and a pace suited to the individual needs of people with autism. They can provide an environment in which individuals with autism can develop skills for the open labour market.

In some sheltered workshops, people with autism produce goods and services that are sold on the open market and receive salaries commensurate with their work and equivalent to the salaries of other workers who do the same type of jobs. Where adequate habilitation, education and training are provided, these workshops can provide a stepping stone towards future jobs in the open labour market, depending on individual abilities and preferences.

Other sheltered workshops (also referred to as 'day activity centres') exist primarily to provide ongoing habilitation activities for people with autism who require a high level of support. While these centres do not require people with autism to work, in the context of habilitation, their activities can include productive work on craft and other manual activities. Primarily funded by governments and or charitable sources, some of these workshops sell the products made by the people with autism to raise nominal funds to support the non-profit organisations that operate them, reinvesting any money raised in the continued development of the workshop in the interests of the people with autism. The existence of these workshops is not financially dependent on any productive output from the people with autism that they support.

While sheltered workshops operate outside of the open labour market, that does not mean that they prevent people with autism from interacting with broader society. On the contrary, sheltered workshops can provide a social environment in which people with autism can interact with the broader public, though usually for limited periods, such as through shops connected to the workshops in which the goods produced by people with autism are also sold by people with autism

or contact with clients who contract the workshop to produce goods. Some people with autism, especially those who are in need of a high level of support, can find interaction with people they don't know to be a stressful experience, and they can prefer to limit these stressful experiences. Sheltered workshops usually adapt the level of contact with broader society to each individual's preferences. Just as a large proportion of other jobs in the open labour market do not involve a lot of interaction with the general public, social interaction can also come from interaction with the local community. Sheltered workshops in which the rights and needs of people with autism are paramount often foster links with their local community to actively encourage the inclusion of the people with autism that they support through regular trips to shops, sporting facilities and community activities.

Sheltered workshops can be an employment solution for those individuals with autism who are in need of a high level of support for whom the open labour market cannot meet their needs and for whom a sheltered environment is more suited, and better able to support, their needs. They can be a viable alternative to the open labour market when, and only when, they prioritise the rights and complex support needs of the individuals that they support. Whenever possible, they should also ensure the transition of people with autism to the open labour market. Certainly, like all other organisations that aim to meet the needs of people with autism, sheltered workshops must strive to make continuous improvements as the field of autism and employment develops and new knowledge becomes available.

More information on sheltered workshops and their relationship to the United Nations Convention on the Rights of Persons with Disabilities is available at:

http://www.autismeurope.org/publications/rights-and-autism-2/

### A step-by-step approach towards the workforce

### Rainman's Home (Austria)

For more than 20 years, a day care centre in Austria – called Rainman's Home – has been supporting adults with autism to develop their cognitive and vocational skills.

Rainman's Home supports around 40 adults with autism each day in two locations in Vienna.

The participants are divided into three groups according to the three stages of the centre's education and training programme.

The first stage (the 'basic 'group) enables participants to work on their basic communication and practical life skills such as cooking.

The second stage (the 'focus' group) engages participants in cognitive training, computer work, cleaning the work area, silk-screen printing, working with wood and clay, outdoor and social activities, sports and music.



Woodwork at Rainman's Home.

The third stage is the group for people with a higher level of autonomy, which focuses on further autonomy training, woodwork, ceramics, housekeeping and gardening.

At all stages, the programme incorporates therapeutic methods to assist cognitive and vocational skills development. It aims to slowly prepare participants for employment, based on the beliefs that transition from the rather protected environment of the day care centre to the 'real working world' should come step by step.

The centre was an initiative of a group of parents who wanted to create daytime activities and further education and employment opportunities for their children with autism upon finishing school, as no such services existed at that time.

More information: www.rainman.at

**TERLAB** (Spain)

### Roles for people who need a high level of support



Paper recycling at TERLAB.

For adults with autism who are in need of a high level of support, it can be very difficult to find suitable employment. TERLAB is a 'sheltered workshop' near Barcelona in Spain which is creating meaningful roles for these adults through activities such as farming, gardening and recycling paper.

Most adults who come to TERLAB usually arrive with very limited skills. TERLAB staff make detailed assessments of each individual's cognitive abilities and functional skills, then create plans for therapeutic treatment tailored to their needs and work according to their abilities.

There are currently 42 adults who participate in TERLAB. Specialised staff work with each participant to improve their skills in relation to interpersonal relationships, communication, behaviour problems, personal autonomy, work activities, physical activities and community involvement, through both therapy and work.

Staff include professionals in the fields of medicine, psychiatry, psychology, teaching, social work and occupational therapy. The participants benefit from the assistance of approximately one staff member for each four participants.

The TERLAB workshop, agricultural land and greenhouses are located in the centre of La Garriga (near Barcelona) to promote the social inclusion of the participants in the local community.

TERLAB is a non-profit initiative of the organisation, Autisme La Garriga.

More information: www.autisme.com



### **Self-determined structures**

Another approach to employment of people with autism is for people with autism to determine the structure and circumstances of their own employment. This can include a person or group of people with autism commencing self-employment or starting their own businesses or other self-managed organisations such as a not-for-profit organisations or co-operatives.

This approach can enable people with autism to overcome difficulties they face in finding a job and working within mainstream work environments; it can be an empowering alternative to the frustrations and challenges of trying to 'fit in' amongst those who don't have autism. Those who choose to develop these structures can gain greater autonomy in making decisions that affect their lives. When considering the rights of people with autism in relation to employment, it is

important to acknowledge the right of people with autism to make decisions in relation to their own employment, as outlined in Article 3 of the United Nations Convention on the Rights of Persons with Disabilities which identifies "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" as a general principle of the Convention. Despite having the right to work within a mainstream workplace, not segregated from the rest of the community, some adults with autism may prefer to work alone or in an environment among others who have autism. Just as most other human beings seek working environments where they feel comfortable, for a person with autism it may be both comforting and empowering to choose to work alone or in a group of other people who have autism.

In self-determined structures, people with autism are still likely to require various forms of support, however, they can be in a position to determine which kinds of support they receive, from whom and when. This can include, for example, support in organisational tasks such as establishing the self-determined structure and setting out work routines, as well as support in social and communication tasks such as seeking and interacting with clients. Given the low economic status of the majority of adults with autism, financial support to establish self-managed employment is also likely to be required.



Administrative work in the Czech Republic.



Office work in Germany.

Self-determined structures for employment of people with autism can be most effective when they involve people with autism who have a relatively high level of intelligence, a good understanding of their own challenges and needs, and relatively strong organisational skills.

# Empowerment at work through a self-managed cooperative

### Laboratorio di Esplorazione Multimediale (Italy)





Staff at the cooperative talking about their work.

In Italy, a group of adults with autism who couldn't find satisfying and accommodating jobs in the open labour market have created a cooperative in which they work together.

Based in Milan, the Laboratorio di Esplorazione Multimediale (Laboratory of Exploratory Multimedia) offers comprehensive services in web design, graphic design, desktop publishing and translation.

It was formed in 2007 after its founders discovered through their conversations on an email list for people with Asperger syndrome that they had a common difficulty to find a satisfying job despite their technical and professional skills.

The cooperative has also translated books on Asperger syndrome into Italian and published them, and completed a project to train a small group of people with autism in digital archiving.

Not only focused on work, the cooperative also organises social and cultural activities for people with autism.

More information: www.lem.coop

### **Other options**

Employment for people with autism should be suited to, or adapted to, each individual's needs in relation to their disability. Therefore there are as many possible approaches to, and structures for, employment for people with autism as there are individuals with autism.

As time goes on, more and more approaches and structures for employment of people with autism are emerging and these can provide useful case studies for ongoing analysis and development of knowledge in this field.

> "f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;"

- Article 27, United Nations Convention on the Rights of Persons with Disabilities

# A different approach to work and inclusion in the community



### Godega4Autism (Italy)

In the Italian province of Veneto, a small village designed to provide homes and jobs for adults with autism is being created.

The village, called Godega4Autism, is an evolving social enterprise project. So far, it includes a building with a dining hall, a kitchen and a workspace as well as agricultural land with a greenhouse.

Since January 2014, two adults with autism have been employed; one of whom is in need of a high level of support and the other is in need of a low level of support. The employees work with a supervisor and an ABA educator, ensuring ongoing education and skill development is part of their work.



The Godega4Autism team with one of their 'hug bikes'.

The employment activities developed so far include assembling 'hug bikes' (tandem bicycles designed to enable a person with autism to ride a bicycle safely with the support of another rider), recycling cork and carrying out projects for local external organisations, such as packaging wine.

For each new work activity, the tasks and processes involved are analysed and visual instructions are produced for employees with autism to follow.

The provincial location, employment and social activities aim to enable the village's residents to interact with, and play a meaningful role in, their local community.

The village is the project of non-profit organisation, Fondazione Oltre il Labirinto Onlus. It aims to be financially sustainable as a result of the work activities as well as ongoing fundraising activities.

### More information: www.oltrelabirinto.it / www.hugbike.it

# Advocacy to gain employment support for people with autism

Autism organisations and other supporters of people with autism can play a key role in creating employment opportunities through advocacy at all levels – from advocacy for individuals to find work, to advocacy with employers and government decision-makers.<sup>88</sup>

As already highlighted in this report, raising awareness about autism, the opportunities, the challenges and skills of people with autism is an essential element to make them visible and foster their participation in the labour market. It is also important to celebrate and promote the organisations that employ people with autism, while emphasising the fact that hiring individuals with autism is not an act of charity – it can be a win-win business decision in which both the business and the individual benefit. Raising awareness about local companies hiring people with autism, for example through media coverage, can help to encourage other businesses to follow their example. Autism organisations should be pro-active in approaching the media through press releases and personal contact.

It can also be effective for autism organisations to regularly network and team up with employers and businesses who already hire people with autism to advocate the benefits to others who could do the same. Creating networking opportunities can also allow exchange of views and expertise between the various interested stakeholders to improve employment practices for people with autism.

Autism organisations can also host public events or meetings on the topic of autism and employment, inviting relevant participants who are in a position to make a difference, such as employers, government decision-makers, media, non-government organisations, philanthropists, people with autism and their families. These events should be positive and aim at inspiring participants about how they can make a difference, initiating a collaborative spirit with participants towards achieving real measurable employment outcomes for people with autism.

In this process, it is also crucial to inform relevant government officials about autism, the need for inclusive employment opportunities and the methods by which these can be made a reality. Autism organisations should initiate close cooperation with relevant government representatives, which can be achieved through the creation of a working group or task force to create employment outcomes for people with autism, aiming at delivering measurable outcomes to increase employment among people with autism.

### Bringing key stakeholders together to create employment opportunities

### **APLA's Together We Can Manage project (Czech Republic)**

The Together We Can Manage project is evaluating approaches to employment for people with autism from across Europe in order to develop a successful model for the Czech Republic.

The project brings together organisations that work with people with autism and similar target groups to evaluate the approaches to employment in various countries.

The project also brings together other key stakeholders including people with autism, politicians, government representatives and employers in the process of creating a policy proposal for the development of supported employment opportu-



A meeting bringing together stakeholders as part of the Together We Can Manage project.

nities for people with autism in the Czech Republic. The policy proposal will be presented to policy-makers and legislators with the aim to have it adopted and implemented.

As part of the project, regular workshops and training sessions on employment for people with autism are also organised with stakeholders.

The Together We Can Manage project is an initiative of APLA, an advocacy and support organisation for people with autism and their families in Czech Republic, with funding from the European Social Funds.

More information: www.twcm.cz

### Employing people with autism in disability organisations

Hiring people with autism within autism or other disability organisations is of course a really good way to lead by example and contribute to raising awareness about their skills. Autism organisations are also in a good position to foster innovation and design efficient models for employing people with autism.



People with autism are increasingly being employed by autism support organisations.

### Changing attitudes and overcoming stigma

### Kuwait Center for Autism (Kuwait)



One of the teaching assistants working with students.

It is not only from Europe that we can find good practices emerging in the employment of people with autism. The Kuwait Center for Autism currently employs four adults with autism within its own services.

The staff who have autism work as library or teaching assistants within a training course for students with autism to learn vocational skills such as wood crafting, life skills, social studies and geography.

They have gained the skills to work in their jobs as a result of participating in the Kuwait Center for Autism's vocational training programme.

The vocational training programme was launched in 2000 with the aim to help people with autism prepare for, and find, suitable jobs. The programme has trained many young people already and there are currently 120 young people with autism participating in it, with the aim to start working in 2015.

The staff of the centre network with companies and other organisations in Kuwait to find suitable jobs for the young people with autism who complete the training.

The employees with autism provide positive role models for the students with autism, as well as demonstrating to other potential employers that people with autism can be very capable at work, thus helping to raise awareness and break down stigma associated with autism.

The Kuwait Center for Autism was created in 1998 and is the first centre for autism established in the Middle East region. Its main purpose is to raise awareness of autism and to offer a range of evidence-based educational services to people with autism.

More information: www.autism2014.net/KuwaitCenterForAutismActivities.aspx



## **People with autism providing training to professionals** The National Autistic Society's 'Ask Autism' project (United Kingdom)



The National Autistic Society's 'Ask Autism' online training is delivered by people on the spectrum.

'Ask Autism' is a new training service of the National Autistic Society, offering a range of products for professional development. Developed and delivered by people on the autism spectrum, Ask Autism provides an 'insider' perspective of autism to give professionals and relevant stakeholders a unique understanding of how people with autism would like to be understood and supported.

The ethos behind Ask Autism is in line with England's autism strategy, titled 'Fulfilling and Rewarding Lives', which recommends that training and service development should be conducted in partnership with people who have autism. The language used by Ask Autism reflects the preferred terminology of people with autism and others involved in the project.

More information: www.autism.org.uk





# COSTS AND BENEFITS OF PUBLIC INVESTMENT IN EMPLOYMENT SUPPORT FOR PEOPLE WITH AUTISM

When analysing the costs and benefits of initiatives to support people with autism to gain and maintain employment, it is useful to first consider the costs of unemployment.

A recent study in the United Kingdom has estimated the cost of support for a person with autism over a lifetime to be between £0.8 million and £1.23 million, depending on their level of support needs.<sup>89</sup> A similar study in the United States estimated the lifetime cost per person with autism to be US\$3.2 million.<sup>90</sup> This study also found that adult care is the largest direct cost within the lifetime of an individual with autism.<sup>91</sup> Most of these adults – between 76<sup>92</sup> and 90<sup>93,94</sup> per cent – are unemployed. While it is very difficult to truly quantify the lifetime differences in costs for a person with autism who is employed and one who is not in employed, these figures clearly demonstrate that the costs of support for unemployed adults with autism are very high.

The cost of unemployment is not limited to the cost of support for unemployed adults with autism. When adults with autism who manage to complete a secondary or tertiary education, cannot gain and maintain employment that is appropriate to their level of skill, or cannot gain employment at all, the costs of their education have, to an extent, been wasted. In addition, the costs of people with autism being unemployed can also include the cost of treating secondary mental health problems resulting from unemployment and social exclusion.

When adults with autism are employed, they are not only able to support themselves (or at least partially support themselves) financially, they are also able to contribute directly to society through their work and through their tax contributions. When a person with autism is employed, the economic advantages are clear – less reliance on government-provided support and a greater contribution to taxes.<sup>95,96</sup>

Of course, support to assist adults with autism to gain and maintain employment requires public investment, and policy-makers must consider the financial, as well as the social, benefits of this investment. Studies have shown that initial costs to establish models of employment support that are effective for people with autism in local contexts can be relatively high, yet their costs can be reduced over the longer term as effective programmes are developed and replicated, and efficiencies are gained.<sup>97</sup> Early studies in the United States demonstrated that employment support services for people with autism required around five years of development before the cost per individual with autism of the service could reach a minimal or even negative level.<sup>98</sup> While it may not be realistic for all employment support services to recuperate their costs, the overall financial benefits of supporting people with autism into employment clearly outweigh the costs.

# From social welfare payments to a more independent life through employment

### Auticon (Germany)



An Auticon consultant at work.

A German IT company is helping adults with autism to support themselves and live more independent lives through employment.

Auticon was founded in 2011 by the father of an autistic son, with the aim of providing jobs in the information technology (IT) sector for people with autism. The company recruits, trains and employs people with autism to work as consultants on IT projects for external clients.

Being employed directly by Auticon enables the staff who have autism to work in a supportive environment with the assistance of job coaches.

Auticon's job coaches and other staff ensure that the business is financially sustainable by handling the management of staff as well as the communication and client-related aspects of the business.

After just a few years, the company now has 49 employees, 26 of whom have autism. It is aiming to employ a ratio of one job coach for each eight employees with autism.

The company is making a big difference to the lives of the adults with autism whom they employ by enabling them to earn their own incomes and live more independently. For example, prior to gaining a job with Auticon, one of the company's employees was living on a disability-related social welfare payment and needed the support of two social workers. After six months, his employment at Auticon enabled him to support himself financially and to develop skills that enabled him to live without the help of the social workers.

Auticon is already operating in six German cities and plans to expand further.

#### More information: www.auticon.de

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# FUTURE DEVELOPMENT OF EMPLOYMENT SOLUTIONS

Autism and employment is a relatively new field of knowledge and practice that remains to be explored further. Some areas of this field that could be developed further in the immediate future include enhancing knowledge through research and sharing good practices, as well as linking job seekers with autism to potential employers.

### **Developing knowledge through research**

At present, there is limited research available on the topic of autism and employment. Research of high academic quality is required to develop an evidence-based body of knowledge in this field. This should include research on approaches to, and practices in, employing people with autism, with a focus on positive outcomes for people with autism.<sup>99</sup> The outcomes measured should be both quantitative and qualitative, including not only employment outcomes but also other outcomes such as of quality of life, educational attainment, residential outcomes and social outcomes.<sup>100</sup>

Research should certainly take into account the diverse spectrum of people with autism, and should aim to identify effective practices and interventions that could serve as the basis to develop guidelines or manuals for others to follow when developing employment services for people with autism.<sup>101</sup>

Future research should also consider outcomes over a longer period of time, rather than just at one specific point in time.<sup>102</sup> Longitudinal studies would be a useful method to evaluate the lasting impact of intervention strategies to assist people with autism into employment, and to inform the development of cost-effective support services.<sup>103</sup>

### Sharing good practices and networking

Those working in the field of employment for people with autism, and people with autism themselves, could benefit significantly from opportunities to share information and learn from each other's experiences. For example, an innovative new international network of organisations that are focused on employing people with autism has been created.<sup>104</sup> Representatives from organisations that assist people with autism into employment from six countries around the world met in Belgium in 2014 to exchange information and discuss the development of new services, methodologies, models, training programs, best practices, and to network around business opportunities. This network, and others like it, could prove to be a very useful way in which knowledge in the field can be developed and shared.

### Linking job seekers with autism to potential employers

Two new websites posting job advertisements specifically for people with autism and for professionals who work with people with autism have recently begun operating in the United Kingdom (www.autismjobs.org) and in the United States (www.autismjobboard.com). Websites such as these have the potential to become very useful resources for people with autism and their supporters, enabling them to search for jobs as well as connecting them to employers who are searching for employees with autism.

# CONCLUSION

Access to employment is a fundamental right, enshrined in the United Convention on the Rights of Persons with Disabilities. Yet, the vast majority of people with autism are unemployed. They are unemployed not only as a result of their difficulties in communication and social interaction, but also as a result of lack of access to education, training and support, and the stigma and discrimination they often face.

The growing number of people with autism and the diversity of their abilities and needs in relation to employment is a significant challenge for national governments and employers across Europe. In this report, we have highlighted a wide range of initiatives from companies, governments and other organisations that are rising to this challenge. These initiatives are connecting people with autism to jobs that match their skills and abilities, and providing the support that is required to help them succeed at work. They are all demonstrating that people with autism can be exceptionally capable and proving that hiring a person with autism can be a mutually beneficial decision.

Supporting people with autism to gain and maintain employment requires public investment in education, training, supported employment programmes and awareness-raising initiatives. As demonstrated in this report, this investment benefits not only people with autism, but the organisations they work for and society as a whole.

With so many adults with autism who are willing and able to work, initiatives to employ people with autism are succeeding all over Europe and around the world. With further investment, the possibilities for the diverse spectrum of individuals with autism to be included in society through employment are endless.



# EASY-TO-READ REPORT ON AUTISM AND EMPLOYMENT

People with autism are able to work.

Some people think:

- that people with autism are not able to work;
- that people with autism are too difficult to work with.

### This is not true.

We call it discrimination when someone will not give a person with autism a job because they think like this.

People with autism have difficulties in communication and social interaction. These difficulties make some parts of working harder for them.

People with autism need support with the parts of working that are harder for them.

People with autism have the right to get support at work. This right is written in the United Nations Convention on the Rights of Persons with Disabilities.

When people with autism have jobs they get paid money.

They can use the money:

- to pay for things they need;
- to live more independent lives.

When people with autism have jobs, they feel more included in society.

In many countries, people with autism are given support to help them to work.

The support includes:

- helping people with autism:
  - to make plans;
  - to prepare for the work they want to do in the future;
- helping people with autism to understand:
  - what they are good at;
  - their difficulties;
  - their needs.
- giving people with autism education and training that is made for them;
- helping people with autism to gain experience in working;
- helping people with autism to apply for jobs and go to job interviews;
- helping people with autism to understand how to talk to other people at work;
- helping other people at work to understand people with autism;
- helping people with autism to stand up for their own rights at work;
- offering people with autism a support person.

The support person can help them at work when needed.

This support is not available everywhere right now.

More support is needed so that all people with autism can work.

Autism-Europe published this report to help everyone to understand the rights of people with autism in relation to work.

People with autism and organisations that support people with autism can use this report to talk to employers and politicians about:

- what makes some parts of working harder for people with autism;
- the rights of people with autism;
- the support that people with autism need to help them to work;
- the benefits of giving people with autism a job.

Autism-Europe is an organisation that works to:

- protect the rights of people with autism and their families;
- share information about the best ways to support people with autism;
- tell people about autism;
- change laws in Europe so that people with autism can have a better life.

This information follows the European standards for making information easy to read and understand. It is designed for people who have an intellectual disability. More information: www.inclusion-europe.com/etr

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