

BRIEFING

Social protection and employment of people with intellectual disabilities

Contributing to the discussion on minimum income and on social benefits
from the perspective of people with intellectual disabilities and their families

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Objective of the paper

All European countries have ratified agreements and conventions on both the European and international level, including the UNCRPD, the International Covenant on Economic, Social and Cultural Rights (ICESCR) which aim to support the rights and capacities of persons with disabilities.

With persons who have a disability and their families being more likely to be impoverished and socially excluded, the report will look at the obstacles that persons with intellectual disabilities face, in particular looking at minimum income and **the eventuality of losing essential disability-related social benefits when entering the labour market.**

The paper will reflect the need to take more action combating social exclusion and poverty of persons with intellectual disabilities. The paper will highlight how those with intellectual disabilities are more likely to be unemployed, or if they are employed, they are working in sheltered workshops without guaranteed minimum wage and other advantages attached to the status of employee. They are also more likely to be institutionalised and under guardianship. The right to choose where and how to live are basic rights that most EU citizens can enjoy but those with intellectual disabilities cannot.

Introduction

“We envisage a world of universal respect for human rights and human dignity, the rule of law, justice, equality and non-discrimination [...] and of equal opportunity permitting the full realization of human potential and contributing to shared prosperity”¹. The adoption of the United Nations Sustainable Development Goals in 2015 marked a clear call for action by the 193 UN members to end poverty, for individuals to live a life of dignity and to promote inclusion. 10 percent of the world population live below the poverty threshold². In a constantly changing world, they are the ones being left behind.

Persons with intellectual disabilities are more likely to be impoverished and socially excluded than those without disabilities. These issues need to be addressed and tackled. The conversation is already happening in the wider political debate, but there is a certainly a need to bring the discussion to Inclusion Europe, sharing knowledge on the key obstacles that persons with intellectual disabilities have and find solutions to overcome them.

This report seeks to do just that drawing on the wider discussion around minimum income and the barriers to social benefits as key features behind growing poverty, and how those with intellectual disabilities are particularly vulnerable to these factors.

Disability and poverty

In Europe, 3 in every 10 persons with disabilities live in poverty and experience social exclusion. This compares to 2 in every 10 persons who have no disabilities³. It is evident that persons with disabilities are more at risk than the general population at being impoverished and being socially excluded. Rates

¹ United Nations General Assembly, Transforming our world: the 2030 Agenda for Sustainable Development. October 2015, available online: https://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E

² The World Bank, ‘Decline of Global Extreme Poverty continues but has slowed’, available at: <https://www.worldbank.org/en/news/press-release/2018/09/19/decline-of-global-extreme-poverty-continues-but-has-slowed-world-bank>

³ EU SILC 2016.

of poverty for persons with disabilities vary greatly across Europe with Bulgaria having a poverty rate of 53.6% whilst Slovakia has the lowest poverty rate at 19.35%⁴.

Disability can be both a cause and consequence of poverty. This is due to people experiencing impoverished conditions being more likely to become disabled (due to a limited access to healthcare and preventive services) and people who are disabled being more likely to live in poverty (due to limited job opportunities, **the risk of losing disability related social benefits when finding a job**, barriers to education and skills development).

Official definitions of poverty are not sufficient when analysing the relationship between poverty and disability, as it is typically referred to as being a “state of being extremely poor”⁵. As stated by the Joseph Rowntree Foundation, poverty should instead be defined as where “someone’s resources (mainly the material resources) are not sufficient to meet their needs.”⁶ Moreover, it should also take into consideration access to services, including access to a good education and healthcare which can be another determining factor and consequence of poverty.

People with intellectual disabilities remain one of the most disadvantaged social groups in European countries. Not only do they and their families face extra costs (for healthcare, logistical and human support etc.) reducing their available resources, but they also have limited opportunities to enter or stay in the labour market⁷.

Economic exclusion of families

Having a member of the family with a disability can impact all aspects of family functioning. Whether it is the financial status of the family, or the difficulty the family faces providing emotional and physical support to the member that is disabled. In the UK, nearly half of the 14.2 million people living in poverty are in families where a member is disabled⁸. The extra costs of supporting a disabled member of the family is one reason for the material deprivation of these families, in comparison to families who do not have a disabled member.

Children with a disability are more likely to grow up in poverty than their counterparts⁹. Growing up in poverty can also increase the chance of a child having poor nutrition and lacking a decent standard of housing.

The employment participation rate of persons with intellectual disabilities is much lower than that of any other person, including persons with other types of disabilities. In Europe, only 44% of adults aged between 21 and 64 who have an intellectual disability partook in the labour force. This stands in stark contrast to the 83% of working-age adults without disabilities who are in the labour force¹⁰.

Sheltered workshops exacerbate the discrimination against persons with intellectual disabilities. Due to the persons working in sheltered workshops not being legally considered as employees, there is no minimum wage or contract, alleviating autonomy for these individuals.

⁴ EU SILC 2016.

⁵ Oxford Dictionary, available at: <https://www.lexico.com/en/definition/poverty>

⁶ Joseph Rowntree Foundation, ‘Disability, Long Term Conditions and Poverty’, July 2014, available at: https://www.npi.org.uk/files/7814/0490/1005/Disability_long_term_conditions_and_poverty.pdf

⁷ Joseph Rowntree Foundation, ‘Disability, Long Term Conditions and Poverty’, July 2014.

⁸ Social Metrics Commission, ‘A new measure of poverty for the UK’, September 2018, https://socialmetricscommission.org.uk/MEASURING-POVERTY-FULL_REPORT.pdf

⁹ Joseph Rowntree Foundation, ‘Disability, Long Term Conditions and Poverty’, July 2014.

¹⁰ Special Olympics, National Snapshot of Adults with Intellectual Disabilities in the Labor Force, 2013, <https://dotorg.brightspotcdn.com/63/42/91ac844b472290b377a2da68222a/siperstein-parker-drascher-jvr-national-snapshot.pdf>

Case study – Estonia

The family lives in the capital of Estonia, Tallinn. The mother has a Masters degree in psychology and she teaches at the university; the father is a linesman. They have two children, the older son is 12 and is severely disabled and the younger is 7 years old. The family owns a private plot from Soviet Union times in the nice area of the city. Both parents work, but the salary rates in Estonia for ordinary people provide the family with less income than the Estonian average.

Because of the lack of money and additional costs required for the disabled child as well as the fact that the family needs to spend more time to take care of their child, their living conditions are below the average standards of living. The family lives in a 30 m² cold, damp wooden house that was constructed 50 years ago. They only have cold water and the toilet is outside the house.

Lack of money and services makes it impossible for the family to take vacations or to spend money for cultural activities. All their income goes to food and first-level basic needs. The low income of the family is not due to the lack of education or to the unemployment of one family members. The reasons of their poverty are low salaries, additional costs caused by disability, insufficient support from the government, and the lack of services.

Source: Estonian Mentally Disabled People's Support Organisation, Estonia, 2005

Living in dignity for people with intellectual disabilities and families

United Nations

The Sustainable Development Goals (SDGs) established in 2015 seek a life of dignity for all with no one being left behind. Whilst all the 17 goals are related, SDG nr. 10 focusing on Inequality is of particular importance. Disability is also referred to in other SDGs, specifically regarding education (SDG 4: Quality Education), growth and employment (SDG 8: Decent Work and Economic Growth), inequality (SDG 10: Reduced Inequalities), accessibility of human settlements (SDG 11: Sustainable Cities and Communities), and when collecting data and monitoring the SDGs (SDG 17: Partnerships for the Goals)¹¹.

While the SDGs provide a political framework, the UN Convention on the Rights of People with Disabilities (CRPD) is legally binding.

The Convention explicitly recognises the rights of persons with disabilities to social protection (Article 28 of the CRPD), as well as the right to an adequate standard of living for themselves and their families, and to the continuous improvement of living conditions.

European Union

The Charter of Fundamental Rights (CFR 2009) contains rights and freedoms under six titles: dignity, freedoms, equality, solidarity, citizens' rights, and justice.

¹¹ More information on the Sustainable Development Goals and the specific goals relating to persons with disabilities can be found at: <https://www.un.org/development/desa/disabilities/about-us/sustainable-development-goals-sdgs-and-disability.html>

In 2010, the European Commission adopted the European Disability Strategy 2010-2020. The Strategy includes the right of people with disabilities to have adequate living conditions through public housing programmes.

The European Pillar of Social Rights (EPSR) was endorsed in 2017 to protect and promote social rights in the EU. It is made up of 20 principles, of which principle 17 is particularly relevant: “People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.”¹² Since, there have been some positive steps including the introduction of the Work-Life Balance for Parents and Carers, and the Transparent and Predictable Working Conditions.

Social protection

Social protection systems can play an important role in supporting the needs of persons with disabilities, especially regarding income security, social health protection and social inclusion.

The “social dimensions of vulnerability such as [...] disability fundamentally shape people’s exposure to risk and their resilience”¹³. Persons with disability are increasingly likely to live in poor households, with limited access to employment opportunities, and with lower education enrolment and attendance rates. This leads to a call for States to intervene more in securing the protection of persons with disabilities.

An issue that arises in many of the frameworks and strategies that the EU has initiated is that for many people with intellectual disabilities, to be given fundamental rights, such as the right to liberty and to a private and family life, one needs financial and practical support. Without this support, those with intellectual disabilities could face social exclusion and poverty, as it could determine whether they are separated from their family and forced to live in an institution or whether they feel able to participate in their community through working.

Whilst income can often be a key measure of the economic well-being of individuals, this may not always be the case for individuals who have a disability or families where a member has a disability who typically face higher costs (such as for healthcare, housing etc.) than those without a disability. An issue in official measurements of poverty is that many figures typically count disability cost benefits as income, even though these are only given to people in order to support some of the extra costs of disability.

Minimum income

Guaranteed Minimum Income (GMI) is a social welfare arrangement that provides citizens or families with enough income to meet their living expenses and may account for the specific needs or costs associated with the household’s disability or long-term illness. Minimum income usually consists of three elements:

- The calculation of the minimum needed by a person to live a good life;
- The set-up of a social safety net (social transfers or loans) allowing people to survive at the social minimum;

¹² European Commission, The European Pillar of Social Rights, available at: https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

¹³ Unicef, Social Protection, available at: https://www.unicef.org/disabilities/index_65315.html

- Provision for targeted assistance like child support, student grants, pensions for the elderly and for those with a disability.

The transfer or loan is usually the largest benefit with other measures being provided in addition depending on the specific categories of people. For those who cannot work, the transfer or loan is usually replaced by pensions for certain categories of people (e.g. elderly or disabled).

The minimum income has three main features:

- **Conditional:** the benefit is provided to beneficiaries meeting some criteria, such as citizenship and a certain income level;
- **Automatic:** the benefit would be paid weekly or monthly, automatically, into a bank account or similar;
- **Withdrawable:** if the beneficiaries do not meet the eligibility criteria anymore, the provision of the benefit can be withdrawn.

Compensation, in contrast, is more specific to the special costs of a person with a disability. The idea is that one should not have to bear the cost of your disability from your income alone. However, not all states offer compensation.

Universal basic income

Minimum Income should not be confused for being Universal Basic Income (UBI) which is a government guarantee made to all adults that allows people to meet their basic needs. It is provided without any condition at the basis of minimum income.

Few countries have implemented Universal basic income.

Policy framework for minimum income

International

Poverty reduction is a primary target of both the Millennium Development Goals (2000-2015) and the Sustainable Development Goals (2015-2030), and the International Labour Organisation (ILO) explicitly mentions minimum income schemes as important tools to reduce poverty and improve living conditions of people, particularly in low- and middle-income countries.

The UN Convention on the Rights of Persons with Disabilities (CRPD), which has been ratified by 177 parties including the EU, has become a key framework of disability rights. Social inclusion is at the heart of the CRPD, which does not just call on states to refrain from discrimination, but calls on them to have measures to implement rights in practice.

European Union

Guaranteed Minimum Income is less prevalent in the EU as member states typically refer to tackling relative poverty, while people's income and living conditions are considerably lower than their country's prevailing standard. Since 1992, the European Union have sought to build frameworks, policies and programmes to reflect the call for social protection systems.

- **2008:** the [Recommendation on the active inclusion of people excluded from the labour market](#) was released, urging EU member states to provide adequate income support, inclusive labour markets design and access to quality services.

- **2010:** the European Parliament produced a resolution on the role of minimum income in the fight against poverty and social inclusion and called on the Commission to support minimum income schemes and good practices from member states.
- **2013:** the [Social Investment Package](#) introduced reference budgets in the design of adequate social protection and income support design.
- **2017:** the [European Pillar of Social Rights \(EPSR\)](#) is the most recent framework for social rights, containing articles on social protection for all workers (Article 12) and minimum income schemes (Article 14), underlining the importance of adequate level of benefits for those who are unemployed (Article 13).
- **2018:** the [Social Fairness Package](#) was launched by the European Commission. It contains among other documents, a proposal for a Council recommendation on access to social protection for all workers, in line with Article 12 of the EPSR.

In most European countries, there are several types of benefits for people with disabilities. There are typically an income-replacement benefits for those with a disability who are not working, and a 'disability costs benefits' which have the objective of covering the additional costs that people with disabilities face.

How does minimum income work in reducing poverty?

In Europe, minimum income schemes are non-contributory schemes of last resort, based on eligibility criteria, aimed at people unable to find work or that are not beneficiaries of other social security benefits. Some schemes also serve as top-ups when other benefits or wages are too low. For people with intellectual disability, it would concern those who are able to work, but who are temporarily out of the labour market, or those who are completely unable to work. Disability and old-age pensions make up the majority of minimum income schemes.

The benefits of these schemes are that they are often targeted with the aim of meeting the needs of the recipient (such as, housing allowances, disability benefits etc.). However, whilst nearly all EU member states have a minimum income scheme, their successes in reducing the number of people at risk of facing poverty were only seen in four European countries by 2015. In contrast, 14 European countries saw only a limited impact on the risk. The effectiveness of the minimum income scheme is limited. Nevertheless in 2013, nearly two-thirds of EU citizens aged over 16 and who have a disability would have been at risk of poverty if they were not recipients of social transfers, e.g. social benefits, allowances and pensions¹⁴.

Issues arise when it comes to the adequacy of the payments where most EU member states have minimum income schemes which are below the at-risk-of-poverty (AROP) threshold¹⁵. Analysing the success of minimum income schemes is more problematic as many member states lack monitoring and research¹⁶. Those with intellectual disabilities often have more difficulties than other groups of people in accessing minimum income schemes due to a lack of funding¹⁷.

¹⁴ European Commission, Disability statistics – poverty and income inequalities, available at: <https://ec.europa.eu/eurostat/statistics-explained/pdfscache/34425.pdf>

¹⁵ European Social Policy Network (ESPN), 'Minimum Income Schemes in Europe: A study of national policies 2015', January 2016.

¹⁶ European Intellectual Disability Research Network, 'Intellectual Disability in Europe, Working Papers', March 2003, available at: <http://www.enil.eu/wp-content/uploads/2012/07/Intellectual-Disability-in-Europe.pdf>

¹⁷ Jane Young, 'Dignity and Opportunity for All: Securing the rights of disabled people in the austerity era', July 2014, available online: <https://www.centreforwelfarereform.org/uploads/attachment/438/dignity-and-opportunity-for-all.pdf>

Disability assessment differences between countries and regions

With the widespread ratification of the CRPD and with many countries experiencing an extended period of austerity, many European countries have revised their definitions of disability and the accompanying assessment mechanisms. Other European countries have sought to adopt assessment systems which are in line with the definition of “disability” in the CRPD.

There are two models of assessment:

1. **The ‘one-stop-shop’ approach:** this is where one assessment is used to determine access to all possible benefits.
2. **The ‘multiple-stops-shop’ approach:** this is where each benefit (and issuing institution) can require a separate assessment, requiring for individuals going to multiple assessments if they require multiple benefits.

In Europe, many countries have some assessments which consider eligibility for several benefits at once. However, for a more specific type of benefit, individuals might have to undergo an additional assessment¹⁸.

A lack of consistency between European countries on assessing disability means any intervention from the European Union is more problematic.

It is important to compare methods between European countries, in order to highlight best practices and find harmonisation when possible.

Disability allowance under poverty line

Despite some efforts from member states to support people with intellectual disabilities, it is evident that minimum income schemes and other forms of benefits have a limited impact on the risk of those with disabilities entering poverty. In 2010, for example, on an equivalised basis (contextual to the size and comparison of the household in which they lived) in the EU15, unemployed persons only received around 43% of the at-risk-of-poverty threshold of all social benefits. In the EU13, it fell to 19%¹⁹.

The largest types of benefit falling under the unemployment benefit category were those of sickness and disability. This was particularly the case in eastern European states such as Bulgaria, Croatia, Romania, Poland and Estonia. These statistics highlight the small amount of unemployment benefits paid to those who are unable to work in these countries as well as across Europe, and how many of the recipients are on sickness or disability benefits.

¹⁸ Lisa Waddington et al., ‘Disability Assessment in European States: ANED Synthesis Report’, September 2014, available at: https://cris.maastrichtuniversity.nl/portal/files/33152854/ANED_2017_18_Disability_assessment_synthesis_report.pdf

¹⁹ Erhan Ozdemir and Terry Ward, ‘Social situation observatory income distribution and living conditions’, February 2014.

There is also a big difference between European countries for those aged 20-59 who are moving from unemployment and where at risk of poverty to employment. For instance, in Croatia, those with disability benefits face a 1.1% reduction in benefits once transitioning to employment. In countries such as Germany, Belgium, France, Finland and Poland the differences are over 20%, even 30.5% in Estonia²⁰.

Case Study – Bosnia-Herzegovina

“The family lives in a village located 15 km from Tuzla. The family members are parents and children, only the father is employed as a construction worker. The mother has completed primary education and is not employed. She spends her time mostly doing house work and she is the main support to her son with intellectual disabilities. The older son is not disabled and has received training to become a car mechanic, but he is not employed. The youngest member of the family, who has an intellectual disability, was born in 1986. He has epilepsy, sight difficulties, two years ago he got diabetes and is currently undergoing insulin therapy. He has completed a special primary school, attended by children with psychical difficulties. He then went to a secondary school for cooks, also within a programme for persons with psychical difficulties.

He is registered at the employment office, but no job has ever been offered to him. Besides, he does not benefit from social support, except for free health care, because he is enlisted at the employment office. He has completed his education with much support from his family. During his schooling period, the only support from the government was free public transport for himself and his support person to and back from school. He also benefited from a monthly child allowance of 30 KM (about 15 EUR) granted by the Social Welfare Centre of Tuzla.

The financial situation of the family is extremely modest. The father, as the only one employed for the past eight years, has a monthly salary of 200 to 250 KM (102 to 127 EUR). The family survives with some additional resources (they work about 1.000 square meters of land, they raise cows and chicken). They spend most of their money on medicines, as they need to buy insulin as well as other medicines. They live in their own house, with good living conditions.

Relations within the family are mostly good. There is understanding for the son with intellectual disabilities but insufficient support from the community has left marks on the family. The mother had to completely devote herself to her son. As a consequence, she neglected her own needs as well as the needs of other family members.

This is a typical situation of a family with a member with intellectual disabilities, indicating the following:

1. Very modest financial situation of the family
2. Insufficient governmental support
3. An insufficiently developed system of social and legal protection
4. Lack of family counselling
5. Training and education are not in accordance with the needs of society
6. There is no support for the employment of persons with intellectual disabilities.”

Source: Association “Korak po korak”, Tuzla, Bosnia and Herzegovina, 2009

Recommendations

²⁰ Erhan Ozdemir and Terry Ward, ‘Social situation observatory income distribution and living conditions’, February 2014.

- Rethink the way that a family's income is measured – the additional costs a person with disabilities in a family must be recognised, as well as the fact that different disabilities have different costs, depending on the type, severity, household composition etc.
- Adjust target mechanisms, benefit frequency and benefit size to account for the added costs associated with treatment, care and mobility that people with intellectual disabilities face
- European countries should strengthen minimum income schemes in the context of an active inclusion of people with disabilities, including drawing on the links between developing an inclusive labour market policy, accessing high quality services, and having adequate minimum income schemes.

Elements of social protection contributing to exclusion from labour market

Social protection systems can play a crucial role in addressing the needs of persons with disabilities. This can be done though offering disability benefits that could provide financial assistance to those who require income support to cover the high costs of having a disability.

How it was:

There are situations sometimes described as “social benefits trap” when a person with a disability is forced to leave social protection benefits to enter or re-enter the labour market, since finding a job yields little to no increase (even a decrease) in their total net income. This is down to the net salary (salary after tax) being same or lower than what their income would be on social benefits.

Option 1 :

There are cases **where people with disabilities are** forced to leave social protection benefits to enter or re-enter the labour market, since finding a job yields little to no increase (even a decrease) in their total net income. This is down to the net salary (salary after tax) being same or lower than what their income would be on social benefits.

As has already been made clear, this is not due to some countries having ‘generous’ social benefits, as most, if not all, European countries have benefits that fall short of the at-risk-of-poverty threshold, with people with intellectual disabilities being particular affected by and failing to lift many out of poverty. Moreover, despite many countries offering benefits for families with a member with a disability, it is usually not enough to cover the extra costs of having a disability²¹. This can mislead many to believe that these families have sufficient resources when this is not the reality.

Another element is when a person with disability loses their support or assistance when they find a job, they are judged as “no longer disabled enough” to receive the relevant benefits or support.

Other causes of labour-market exclusion

Segregated education

For a long time, parents of children with intellectual disabilities have been calling for inclusive schools, how in line with the UN CRPD.

In many European countries, children with intellectual disabilities still attend special schools that allow little interaction with non-disabled children and do not provide children with equal opportunities to

²¹ Social Metrics Commission, ‘A new measure of poverty for the UK’, September 2018, https://socialmetricscommission.org.uk/MEASURING-POVERTY-FULL_REPORT.pdf

flourish. This impacts not only their childhood but also their ability to enter the labour market due to a lack of preparedness and skills needed. There are not enough vocational trainings to prepare young

Good practice – Germany

Sophie-Scholl-Schule in Gießen was set up in 1998 as an inclusive school for all children. Accepting and appreciating heterogeneity is emphasized in developing teaching methods, school rituals and activities. Multi-professional teams of teachers, educators and therapists work together and accompany all children during the school day and parents find many opportunities to cooperate with the school.

Source: *Inclusion Europe, 'Towards Inclusive Education', 2018, available at: https://inclusion-europe.eu/wp-content/uploads/2018/02/Best-Practice-Education_EN-FINALWEB.pdf*

Case study – France

“My little boy is deprived of school since his first comeback last year since September 2018. In the village where I live in the Var, the communal school has one member of staff for 19 students per class and it is not open to children with disabilities. My son has a language delay and is hyperactive, and the teacher from the first day blacklisted him, saying that it was the best way for him to develop [...] We decided to remove our son from this school and requested a waiver for the nearest town.”

Source: *Jaipasecole, available at: <https://marentree.org/les-temoignages>*

people with intellectual disabilities for jobs. There is a general lack of employment-oriented support for teenagers and young adults in special school.

Labour market discrimination

In the past, people with intellectual disabilities were often treated as unable of participating in the 'open' labour market – in other words, forms of employment where an applicant would have to follow a competitive recruitment process to obtain the position.

'Sheltered employment' is where people with intellectual disabilities are placed in what is often a residential institution and can perform some form of work in a segregated environment. Across Europe, the limited number of schemes that integrate persons with intellectual disabilities into the general employment sector have led to many having to work in sheltered workshops or occupational therapy facilities. This could lead to those with intellectual disabilities:

- Having no independent social security;
- Not subject to employment protection laws;
- Having no more legal representation;
- Not eligible for retirement;
- Not receiving formal wages (some states offer “pocket money” of around 20-50 EUR a month)²²;

²² Academic Network of European Disability Experts (ANED), 'Report on the employment of disabled people in European countries', Austria, April 2011, available at: <https://www.disability-europe.net/downloads/292-at-employment-report>

- Deprivation of legal capacity (e.g. the right to open a bank account, manage their own money, sign contract).

This all means that those working in sheltered workshops have little economic independence. In most European countries, the majority of ‘employees’ in the sheltered workshops are people with intellectual disabilities. This means that those with intellectual disabilities, although not being seen as ‘unemployed’ do not enjoy the same rights than employees in the open labour market. People with intellectual disabilities are almost totally excluded from the world of work, which reinforces their risk of becoming impoverished and socially excluded.

When working in the open labour market, people with intellectual disability often value the greater autonomy and the opportunity to expand their social networks, which they had previously been denied due to the general lack of include education for persons with intellectual disabilities. There is also typically a greater variety in the type of work available in the open labour market, encouraging personal development. However, in most European countries, even when people with intellectual disabilities are active in the labour market, their experience of employment differs from that of other workers. They are more likely to be in part-time work, clustered in low status work and receiving low wages. The job requirement and expectations might also not match that of the employee’s skills.

Possible solutions

Job carving

Job carving is a supported employment strategy when a company creates a position specifically to fit a person’s skills and talents. It means creating, modifying, or customising what is typically a community-based job so that it can be performed by persons with disabilities, which will also meet the needs of the employer. It is a way for persons with intellectual disabilities to find *meaningful* employment where they are given the independence that they are denied under sheltered workshops.

Job carving can also open up an opportunity for those with intellectual disabilities already employed in the open labour market, where an employee can adjust their job description and tasks to meet their skills and abilities. This both puts more agency to the employee, and also increases wellness in the workplace. This also benefits employers who will experience greater engagement from their employees, helping to boost the emotional commitment between an employee and a company.

Good practice – Germany

KLAPjob

Landforeningen LEV, based in Denmark, works to improve the living conditions for persons with intellectual disabilities and their relatives. The Klapjob method aims to give persons with intellectual disabilities employment in the open labour market. The Klapjob Methods first contacts HR-departments to sell the idea of the scheme who will then share it with their companies with a focus on the needs of the company. Nationwide companies have many branches and in each branch one or more jobs are identified. The vacant jobs are advertised on www.jobnet.dk.

Job sharing

Job sharing is an employment arrangement where typically two people are retained on a part-time or reduced-time basis to perform a job normally fulfilled by one person working full-time. Job sharing,

like other flexible work arrangements, can help companies to recruit and retain employees, including employees with intellectual disabilities. It is a means of making a reasonable adjustment in the workplace to allow a person with a disability to be employed if their disability prevents them from working full-time.

Living wage

A living wage is the minimum income necessary for a worker to meet their basic needs. In contrast to a minimum wage which most European countries have, a living wage ensures the wage a worker earns in a standard working week is sufficient to afford a decent standard of living for themselves and their family. With persons with disabilities typically facing higher costs than those without disabilities, national governments could implement a minimum living wage, especially for those with disabilities.

Minimum income

Whilst national governments should implement measures promoting the inclusion of persons with intellectual disabilities into the open labour market, not all those with disabilities are able to work. In these cases, they should be protected through social assistance including adequate minimum income. The EU has not prioritised a rights-based approach when referring to minimum income in Country Specific Recommendations²³. Instead, the EU followed an approach advocating for finding means to promote employment rather than asking national governments to have a sufficient minimum income for a dignified life as a right.

Minimum income should go beyond covering the costs of food and shelter and understand the individual needs of persons who are without work. Those with intellectual disabilities are likely to face higher costs due to their disability in contrast to the general population. The minimum income in each European country should reflect this and follow a rights-based approach serving those most in need first.

²³ European Anti-Poverty Network, 'Social Rights and Social Plight', September 2017.

Good practice – Austria

SPAGAT

Institut für Sozialdienste is a large multi-disciplinary, politically independent, non-denominational organisation supporting people with social problems or questions in the Austrian province of Vorarlberg. One department of the Organization is “ifs Assistenz”.

“ifs Assistenz’s work is based on the strengths and abilities of our clients. The objective is to strengthen people with disabilities in their personal responsibility and autonomy, as well as to allow and promote self-determination and independent living (work, housing, leisure time, further education, etc.) for all involved.

The main objective is to bring people with high support needs into meaningful, freely chosen and paid employment in the open labour market. We promote participation and exchange between all stakeholders involved in the integration process: employers, mentors, clients, family, friends, teachers, etc.

SPAGAT connects and launches processes concerning integration into living and leisure-time in order for people with disabilities to be able to lead a life in their own communities as part of society. ifs SPAGAT is a model for the integration of persons with disabilities into the employment world. It provides support and help to find work in the open labour market.”

Source: EASPD, 10 Best Practices in Employment Support for People with Disabilities, 2013, available at:

https://www.easpd.eu/sites/default/files/sites/default/files/PressReleases/annex_3_10_best_practices.pdf

Labour market regulation

National governments should implement an effective disability policy tackling all stages of entering and exiting the labour market, with measures in place to ensure early and well-targeted access to high-quality rehabilitation services whilst also providing cash transfers for those in need²⁴. This is not the case in most EU member states.

Governments could compensate new employees for the additional expenses which come with going to work, or temporarily reducing the taxation level for people who transition from benefits to the labour market. This is the case in Austria, where there is a tax exemption for those who have over 50% disability.

Inclusive education is also something that should not be overlooked. The majority of people with intellectual disabilities in Europe often only attain primary education, with many not going on to pursue secondary and upper secondary education. This has a knock-on effect on entering the open labour market, with a lack of education dramatically reducing the chances of entering the open labour market²⁵. Considering this, national governments can do more to make their education system inclusive, as well as encourage the creation of more vocational trainings with companies to ensure that persons with intellectual disabilities have the skills to work in the open labour market.

²⁴ European Commission, ‘Disability and labour market integration’, May 2016.

²⁵ Inclusion Europe, ‘Poverty and Intellectual Disability in Europe’, 2009.

Housing

Building human connections and feeling part of a group and community are essential to fulfil human needs. Despite Article 19 of the CRPD stating the right of all people to choose where and with whom to live, in reality it is very different with many living in institutions and group home. Living within a community can offer the best protection for persons with intellectual disabilities and their families in the long-term. It is an opportunity for them to experience more self-determination, more choice and contact with friends and family.

Institutions and group homes are not sufficient in providing good outcomes for persons with intellectual disabilities. Indeed, these forms of housing are relatively weak in regard to social inclusion, independence, material well-being, personal development and rights. Those living in institutions are more likely to feel loneliness and are less likely to be able to see family. Persons living in institutions have also demonstrated a clearer wish to somewhere else, compared to those living in their own home or with family²⁶. Moreover, the outcomes of living in an institution for those with complex support needs are not adversely impacted by where they live. Indeed, they might actually benefit from a less structured living setting.

Accessible housing for people with intellectual disability is of great necessity. Crucially, access to suitable and secure housing remains largely on affordability, especially in countries where buying and renting costs continue to increase. Yet, as has already been made clear in this report, persons with intellectual disability typically lack the financial resources needed due to a discriminatory labour market and inadequate minimum income.

Case Study – Marija S., Croatia

“Once you enter, you never leave” Marija S. said of her new home with intellectual and/or mental disabilities in the city of Karlovac, Croatia. Marija, a young woman in her 20s, had entered the institution, innocuously named the Center for Therapy and Rehabilitation ‘NADA’ (meaning ‘Hope’), six months earlier in June 2009.

Marija’s situation is complex but not uncommon: she has both mild intellectual and mental disabilities that limit her participation in society. Since her family has not always been able to care for her, Marija has lived in institutions for most of her life—but not always. Directly before arriving at NADA, Marija lived for two-and-a-half years in an independent living program in Zagreb which provided housing and support for persons with intellectual disabilities. Here, Marija was able to experience life in the community—working, taking care of her own needs, and coming and going as she pleased.

But as Marija’s mental state deteriorated, she was forced to find another living situation, one that could support persons with mental, and not just intellectual, disabilities. Since there were no similar supportive community living programs for persons with mental disabilities in Croatia, and Marija could not live on her own without support or with her family, there was no choice but to send her back to an institution—NADA. Initially, Marija’s therapists talked with her about one day moving back into the community. “There, I was free,” Marija said. But as the months passed, such discussions waned, along with Marija’s hope that she would ever live outside an institution again.

Source: Deinstitutionalisation of Persons with Intellectual Disabilities in Croatia, Human Rights Watch, 2010, available at: <https://www.hrw.org/report/2010/09/23/once-you-enter-you-never-leave/deinstitutionalization-persons-intellectual-or>

²⁶ National Core Indicators, ‘Housing for People with Intellectual and Developmental Disabilities: How do we Ensure a Home of their Own?’, available at: https://www.nationalcoreindicators.org/upload/presentation/Housing_NASDDDS_final.pdf

Segregation in institutions

Whilst the number of people with intellectual disabilities staying in large institutions has decreased, there is still a long way to go. Moving towards community-based care and closing down institutions is one mean of promoting the inclusion of persons with intellectual disabilities. Deinstitutionalisation is about expanding the welfare state to cover groups that were left behind²⁷. It is essential for national governments to formulate a clear plan for deinstitutionalisation and prevent further institutionalisation. Alternative community-based programmes are typically not more expensive and are sometimes cheaper than institutions.

Good practice in Norway and Sweden

Deinstitutionalisation

During the 1990s, Norway and Sweden shifted from downscaling and improving institutions to full deinstitutionalisation. Norway became the first country to close all its institutions. Whilst following similar methods (e.g. reforming existing legislation), they also had different processes. Norway almost exclusively abolished most special legislation and introduced new articles to existing laws on social care. However, by the mid-1990s, local governments in Norway and Sweden were made fully legally responsible for services, a key measure in the process of replacing institutions with community-based care.

Source: Jan Tøssebro, 'Scandinavian disability policy: From deinstitutionalisation to non-discrimination and beyond', European Journal of Disability Research 10, 2016.

Inadequate healthcare

Poverty is not just about financial hardship, but also relates to access to services. People with intellectual disabilities typically have worse physical and mental health than those without a learning disability. Moreover, they are at greater risk of death despite being in many cases preventable. In the United Kingdom, for example, the life expectancy of women with an intellectual disability is 18 years shorter than for women without a disability. For men, the difference is 14 years.

There is a big difference in inequalities when it comes to access and quality to healthcare. This is largely due to:

- A lack of accessible transport links (particularly the case for those living in rural areas);
- Patients not being identified as having an intellectual disability;
- Staff having little understanding about intellectual disabilities;
- Failure to recognise that a person with an intellectual disability is unwell;
- Inadequate aftercare or follow-up care.

European countries also have a legal obligation to provide an adequate healthcare, with Article 25 of the CRPD stating that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discriminations on the grounds of their disability. It is important to address the issue of unequal access to healthcare as to receive poor healthcare services means that an individual could have poorer health outcomes as a result.

²⁷ Jan Tøssebro, 'Scandinavian disability policy: From deinstitutionalisation to non-discrimination and beyond', *European Journal of Disability Research* 10, 2016.

Training and awareness-raising of health professionals

This is not only about access to medical information, but it is also about building communication strategies supporting a stronger human rights approach to disability. Medical schools and other medical training institutes should integrate an intellectual disability awareness training in their courses. The post-2020 European Disability Strategy can do more to promote awareness of intellectual disabilities in medical schools.

This also links to the communication of medical professionals to persons with intellectual disabilities. A 2017 survey carried out by Inclusion Europe found that 100% of the respondents reported that medical professionals often prefer to communicate with the support person instead of directly with the patient with an intellectual disability²⁸. Lack of direct communication can be a major obstacle to accessing healthcare. This reinforces the need to train medical practitioners and staff to communicate directly with persons with intellectual disabilities.

Good practice – United Kingdom

Purple All Stars

In the UK, the Purple All Stars have developed a sepsis song to raise awareness and improve vigilance to the signs of sepsis amongst people with an intellectual disability. A supporting video has been developed so that the song and its message can be shared widely : [video](#).

In-work poverty

Employment does not make the risk of poverty disappear. In-work poverty refers to those who are impoverished despite being employed, viewed as where household earnings are less than 60% of median national income. In 2016, the average percentage of employed persons aged 18 and over who were at risk of in-work poverty stood at 9.6% with Romania having the biggest percentage of nearly 19%, whilst Finland had 3%²⁹. Compared to 2010, the percentage of in-work has grown in most member states. Governments have sought to combine a variety of methods (e.g. minimum income, minimum wage, tackling labour market segmentation) to tackle this.

Nevertheless, in-work poverty is not the stated policy goal for these measures and can actually be overlooked. Indeed, issues such as the cost of housing and healthcare, means that in-work poverty is even more likely and national governments tend to lack measures addressing these issues. Moreover, in-work poverty is higher for those who have a low level of education³⁰. Again, this particularly makes those with intellectual disabilities more vulnerable due to most European countries having a lack of inclusive education leading, limiting their chance of interacting with non-disabled children and further limiting their chance to flourish.

²⁸ Inclusion Europe, 'Un-equal healthcare? Study on equal access to healthcare for people with intellectual disabilities', 2017, available at:

https://inclusion-europe.eu/wp-content/uploads/2018/03/Study_equal_access_health_care_EN.pdf

²⁹ EUROSTAT, 'In-work poverty in the EU', March 2018, available at:

<https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20180316-1>

³⁰ European Commission and the European Social Policy Network (ESPN), 'In-work poverty in Europe: a study of national policies 2019', May 2019.

CONCLUSION

This report has outlined the relationship between poverty and social exclusion, and persons with intellectual disabilities. It is evident that individuals with a disability and families who have a member with a disability are more likely to live in poverty and be socially excluded. Poverty not only refers to a status of being extremely poor, but also incorporates limited access to services.

Those with intellectual disabilities continue to be excluded from the very beginning with a lack of access to education to lack of the labour market, leading to them being held back when accessing a job, limiting income, autonomy and inclusion. Even when they can find and retain a job, low wages and the likelihood of having to work part time, with the addition of having reduced benefits due to being employed, means that persons with intellectual disabilities and their families are still at risk of living in poverty. Social protection for all is essential in combatting poverty and risk of social exclusion.

In order to tackle issues regarding employment, both national governments and companies have a responsibility with the former needing to implement measures to regulate the labour market, and the latter in tailoring jobs better suited for persons with intellectual disabilities through job carving and job crafting. When it comes to social inclusion, there is a clear need to reform issues regarding housing (e.g. institutionalisation), healthcare and education as key determinants behind inclusion.

Appendix

Examples of job carving

SOPA

SOPA is also another example of supporting job carving. They do this by:

1. Developing job seeker profile (strengths, risks and success factors, skills) leading to case analysis;
2. Gathering information from businesses, e.g. list of employers, discuss expectations of employees.
3. Identifying carving tasks
4. Job coaching: teaches employees to fulfil tasks, provides emotional support and find means of natural support.

I-Diverso projecto

I-Diverso projecto aims to share good practices and mutual learning on job-design, job and language coaching, and validation of required competences. It has developed an integrated model of inclusive job-design, which has been tested in 30 companies. Its method seeks to create new jobs without disturbing the sustainability of the existing work environment. It also involves individual coaching, allowing for greater personal development of employees.

LINO

Based in Malta, LINO aims to assist people with intellectual disabilities get onto the open labour market. The project started with the Maltese government enforcing a 2% quota. LINO aims at supporting companies to create jobs for persons with intellectual disabilities and provides incentives for them. The corporate relations unit in a company would meet with employers. LINO supports people with intellectual disabilities before they enter the labour market and afterwards. This results in persons with intellectual disabilities being included in the open labour market, increasing employment opportunities and job retention. This also supports their feeling of empowerment, personal and professional development.

ENABLE Scotland

Established in 1954, ENABLE Scotland seeks to follow a rights-based approach for employment. They help social people with intellectual disabilities, and specifically those with complex special needs, to get a job. They support employment through:

1. In-work support (job carving and job coaching);
2. Overcoming financial and social barriers;
3. Fair Financial Recognition;
4. Preventing in-work poverty;
5. Continued career development.