

Poverty of persons with disabilities and their families

Policy Briefing

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Objective of the paper

The targets of the **Sustainable Development Agenda 2030** make it clear: to achieve a world that is sustainable, just, equitable and inclusive of all people, including persons with disabilities, poverty must be eradicated. However, despite efforts people with disabilities remain disproportionately affected by poverty and social exclusion across Europe, impacting their social and socio-economic status, such as education, employment, and social support, wellbeing and access to opportunities. Yet, poverty has many more implications on the lives of persons with disabilities and their families, creating additional barriers to participation and inclusion.

This briefing explores the social perspective of poverty, its causes and its effects on the lives of persons with disabilities and their families, showing why it is essential to **eradicate poverty to achieve the full inclusion of persons with intellectual disabilities and their families**.

Introduction

29 million persons with disabilities (28,7%) across Europe are currently **at risk of poverty** or social exclusion.¹ In 2018 overall risk of **household poverty** or **social exclusion** for persons with disabilities living in the European Union (EU) was 34,6% versus 19,9% for persons without disabilities.²

At risk of poverty or social exclusion: Measures the share of people with an equalised disposable income,³ after social benefits, below the at-risk poverty threshold. Or those materially deprived for example those who are unemployed.⁴

Household poverty: Includes households that have equalised income below 60 % of the national average.⁵

¹ Poverty and Social Exclusion of Persons with Disabilities, EDF, 2020.

² Information retrieved from European SDG Summit, 2020.

³ Equalised disposable income is the total income of a household, after tax and other deductions.

⁴ EU social indicators dataset, European Commission, <https://ec.europa.eu/social/main.jsp?catId=818&langId=en>.

⁵ Household composition, poverty and hardship across Europe, Eurostat, 2013, <https://ec.europa.eu/eurostat/documents/3888793/5856569/KS-TC-13-008-EN.PDF>.

Reasons for that are a multitude of socio-economic, environmental and participation barriers, that people with disabilities and their families encounter in their everyday lives.

These barriers can be:

- Inaccessibility of the environment;
- A lack of employment and opportunities;
- Low waged work opportunities;
- Extra disability related costs;
- Cuts in disability benefits;
- Family members forgoing employment and subsequently income, or education to take over the role of a caregiver at home.

All these factors have a negative economic consequence on the individual as well as on their families, and often reduce options to escape poverty.⁶ Poverty can also affect many other areas of life, for example: participation, access to leisure activities, adequate housing and living as well as the physical and psychological well-being of families and the individual.

"The critical need to address the negative impact of poverty on persons with disabilities" is also recognised in the preamble of **the UN Convention on the Rights of people with disabilities (UN CRPD)**. In its Article 28, the Convention states the necessity for persons with disabilities to access an adequate standard of living and social protection, such as poverty reduction programs. It also exerts the right of persons with disabilities and their families to receive assistance from the State regarding extra-disability related costs, training, counselling and care.⁷

In 2015, the United Nations General Assembly set disability as a cross cutting issue in its Sustainable Development Agenda 2030, as persons with disabilities are disproportionately affected by poverty and exclusion worldwide. As a consequence, several **Sustainable Development Goals (SDGs)** directly include people with disabilities with clear indicators, to

⁶ Disability and poverty: two related conditions. A review of the literature, Mónica Pinilla-Roncancio, 2015, http://www.scielo.org.co/scielo.php?script=sci_arttext&pid=S0120-00112015000500014.

⁷ Convention on the Rights of Persons with Disabilities, 2006, <https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx>.

create an inclusive, accessible and sustainable world for everyone. Goal 1 aims at 'ending poverty in all its forms everywhere'. Its targets refer to ending hunger and ensuring safe access to food safety, implementing national social protection systems, measures and social security guarantees by 2030 and ensure access to financial services "in particular to the vulnerable".⁸ The right to protection against poverty and social exclusion is also enshrined in Article 30 of the revised European Social Charter.⁹

The EU recognised poverty as a key challenge in its **Europe 2020 strategy for smart, sustainable and inclusive growth**. However, the European Commission also noted that not all EU citizens have benefitted equally from the measures taken under the strategy, such as persons with disabilities, and remain at a higher risk of poverty and social exclusion in Europe.¹⁰ The **European Pillar of Social Rights (EPSR)** is the main policy instrument at EU level to combat poverty and enhance social rights. Pillar 7 of the EPSR refers to the inclusion of persons with disabilities in all areas of life, such as education, employment, reasonable accommodation and income support.¹¹ However, the Social Scoreboard currently does not measure the implementation of the EPSR in regard to persons with disabilities and the obligations outlined under the UN CRPD.

Moreover, the evaluation of the **European Disability Strategy 2010-2020** has shown that poverty and social exclusion levels have not substantially changed for persons with disabilities over the years, and that the gap between persons with and without disabilities has actually widened. While poverty and social exclusion decreased by 2.4 % for persons without disabilities, it only decreased by 0.5 % for persons with disabilities.¹²

This shows that not much has changed throughout Europe to reduce people with disabilities' poverty level and to combat social exclusion. Despite some efforts, barriers seem to remain.

Country specific data

⁸ UN Flagship Report on Disability, 2019, <https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf>.

⁹ European Social Charter (Revised), Strasbourg, 3.V.1996.

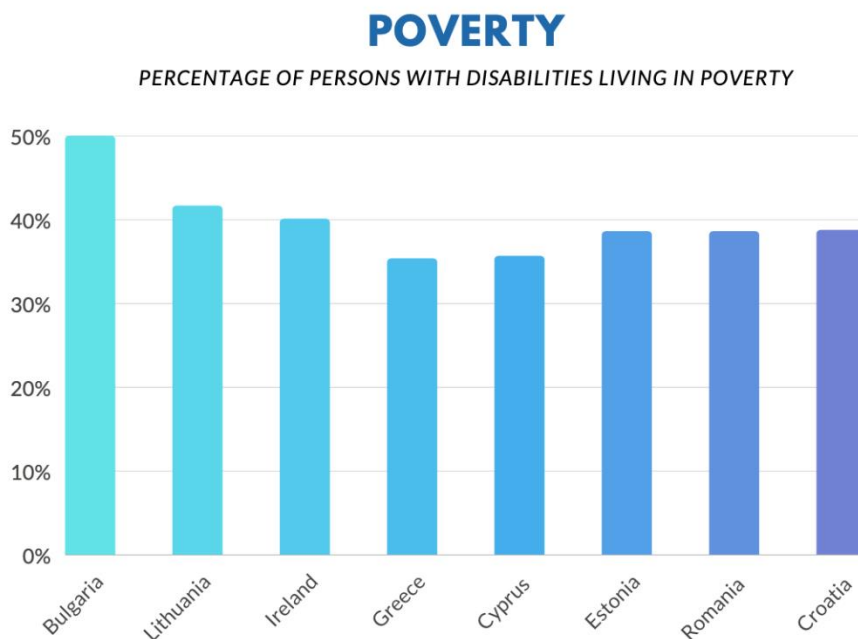
¹⁰ Poverty and social exclusion, European Commission, <https://ec.europa.eu/social/main.jsp?catId=751&langId=en>.

¹¹ The European Pillar of Social Rights in 20 principles, https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en.

¹² Commission staff working document evaluation of the European Disability Strategy 2010-2020, <https://europa.eu/lqn64Jb>

In Spain 44.9% of persons with disabilities aged between 16-64 years are at risk of poverty and social exclusion, and the poverty risk rate of employed persons with disabilities is of 14.9%, amounting to 253,493 people. ¹³

In Switzerland 14.5% of people with disabilities lived in 2015 in a household whose disposable income was less than 60 % of the Swiss median income. ¹⁴



Alt-text image: Percentage of persons with disabilities living in poverty: **In Bulgaria** over 50% of persons with disabilities are at risk of poverty. In **Lithuania** 41.65%, in **Ireland** 40.9%, **Greece** 35.35 %, **Cyprus** 35.65 %, **Estonia** 38.6 %, **Romania** 38.6% and in **Croatia** 38.75%. ¹⁵

In Austria, people with disabilities are more than twice as likely to be affected by poverty, a survey revealed that 84,000 persons with disabilities experience income poverty or exclusion. ¹⁶

¹³ Fundación Once, <https://www.odismet.es/indicador-basico/216tasa-de-riesgo-de-pobreza-de-la-poblacion-con-discapacidad-ocupada>.

¹⁴ Armut, Bundesamt für Statistik, <https://www.bfs.admin.ch/bfs/de/home/statistiken/wirtschaftliche-soziale-situation-bevoelkerung/gleichstellung-menschen-behinderungen/lebensstandard/armut.html>.

¹⁵ Poverty and Social Exclusion, European Disability Forum, 2020.

¹⁶ Armutsrisiko für Menschen mit Beeinträchtigung, Vertretungsnetz, 2015, https://vertretungsnetz.at/fileadmin/user_upload/7_News/Rundbrief_10-15_Norbert_Krammer_Armutsrisiko_fuer_Menschen_mit_Beeintraechtigung.pdf.

In France, half of people with disabilities have a standard of living of less than 1,540 euros per month, which is almost 200 euros less than that of persons with no disability. Moreover, it is found that the more severe the impairment, the lower the income and the higher the level of poverty. It is estimated that 30% of people with 'severe mental limitations' live below the poverty line, compared to only 10% those with hearing impairments.¹⁷

In Germany, one in five persons with a disability is at risk of poverty, and especially people in employment.¹⁸

Adults with disabilities living in **England**, are twice as much at risk than their counterparts to experience a high difficulty in covering expenses, such as bills, medical bills and are thus also less likely to set long-term financial goals.¹⁹

The data above makes it painfully clear: people with disabilities are across Europe at a higher risk of poverty. While there is available data on persons with disabilities at-risk of poverty or social exclusion, it is important to note, that disaggregate data by type of disability, gender, demographics and by type of employment is not collected at EU level. This makes it difficult to assess where support and targeted interventions are most needed.

➔ Data collection in a disaggregate way, and in line with the UN CPRD, is of the utmost importance to inform evidence based policies and demonstrate where specific and targeted support is needed.

Women with disabilities

Women with disabilities are at a higher risk of poverty because they face multiple and additional intersecting barriers, such as higher risk of unemployment and a pay gap, which impacts their financial resources. All these factors make it even more difficult to meet extra disability related costs, which are not fully covered by benefits.

¹⁷ Le niveau de vie des personnes handicapées : des différences marquées selon les limitations, DREES, 2017, <https://drees.solidarites-sante.gouv.fr/IMG/pdf/er1003.pdf>

¹⁸ Armutsrisiko bei Behinderung: Jede/r fünfte ist gefährdet, DGB, 2020, <https://www.dgb.de/themen/++co++62165a8a-8dec-11ea-b6e6-52540088cada>.

¹⁹ Crippled, Austerity and the Demonization of Disabled People, Frances Ryan, 2019.

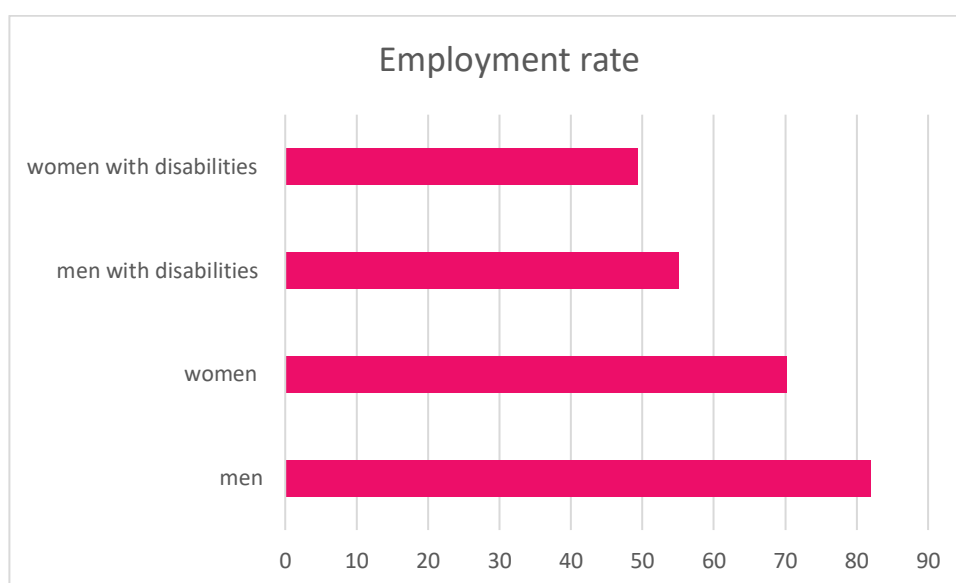
In **Bulgaria**, 57.2 % women with disabilities are at risk of poverty and social exclusion, which is 7.2% higher than men with disabilities.

In **Romania** women with disabilities are 6.8 % more at risk of poverty than men with disabilities.

In **France** women with disabilities are 4.4 % more at risk of social exclusion and poverty than men.²⁰

In 2019 the Council of the European Union affirmed that almost **a third of women with disabilities are at risk of poverty or social exclusion**, which according to the Council of the European Union is mainly due to additional employment challenges faced by women.²¹

In fact, 49.3% of women with disabilities were employed in comparison to 55.1% of men with disabilities (2018). In comparison to women with no disabilities: 70.2% and men 82%.²²



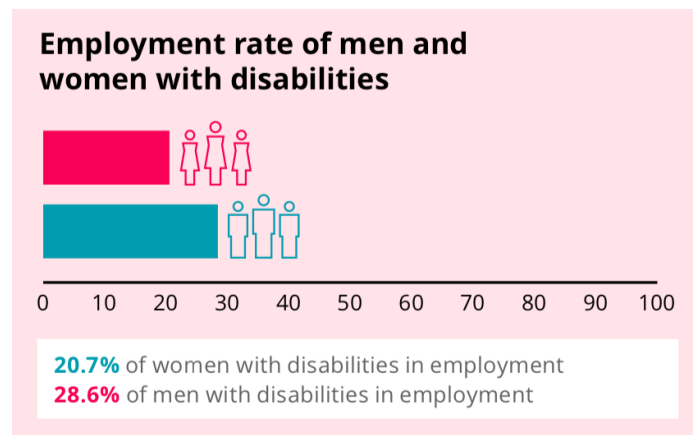
This graphic shows how women with disabilities have the lowest employment rates compared to the other groups.

²⁰ Poverty and Social Exclusion, European Disability Forum, 2020.

²¹ The 5th Review of the Implementation of the Beijing Platform for Action in the EU Member States, Council of the European Union, November 2019, <https://data.consilium.europa.eu/doc/document/ST-14254-2019-ADD-2/en/pdf>.

²² Sustainable development in the European Union monitoring report on progress towards the SDGs in an EU context, Eurostat, 2020.

Moreover, only 20.7% of women with disabilities are in full time employment, compared to 28.6% of men with disabilities.²³



→ Extra attention has to be paid to women with disabilities across the EU. The European Gender Equality Strategy and the EU Gender Action Plan must address **multiple and intersectional discrimination** against people with intellectual disabilities, with a particular focus on women with intellectual disabilities.

Causes of Poverty

Unemployment and in-work poverty

In the European Union, only 50.8% of persons with disabilities are in employment, compared to 74.8% for persons without disabilities.²⁴

In **England**, by the age of 26, people with disabilities are four times more likely to be unemployed than people their age without disabilities.²⁵

In **Croatia**, a downward trend can be observed in the employment of persons with disabilities. In 2020 employment decreased by 21.4%. Among the unemployed persons with disabilities, those with intellectual disabilities account for the largest percentage with 30.5%.²⁶

²³ Gender Equality Index 2019.

²⁴ EU SILC 2017.

²⁵ One in five people say they would be less likely to employ disabled persons', Leonard Cheshire, 2017.

²⁶ Croatian Employment Service (2020). Report on the activities of the employment service in area of employment of persons with disabilities in the period of January 1st, to September 30th, 2020).

Even though data on the employment situation of people with intellectual disabilities is scarce, the little information available clearly shows that the percentage of people with intellectual disabilities employed is extremely low.

In **Ireland**, according to the National Intellectual Disability Database:

- 36% of adults with an intellectual disability were in some form of work,
- 29% in sheltered workshops,
- 7.1% were working in the open labour market.²⁷

When employed in the **open labour market**, people with intellectual disabilities are often paid below minimum wage, work part-time and have precarious work contracts. More often, people with intellectual disabilities are steered into **sheltered workshops** where they are segregated, do not receive minimum wages and are not protected by labour laws.

Currently, persons working in sheltered workshops in **Germany** receive an hourly pay of €1.30.²⁸

- To increase the participation of people with intellectual disabilities in the labour market, the implementation of the **job coaching** and **job carving** schemes and heavy investments in the transition from education to employment are needed.
- To specifically address unemployment barriers by persons with intellectual disabilities, **data** must be collected by type of disability and by gender, as well as include persons who are inactive, persons living in collective households, in institutions and work in sheltered workshops.
- The labour rights of people working in sheltered workshops must be recognised.
- **Targeted social and employment policies** must be developed to address unemployment rates of people with intellectual disabilities as well as the multiple and intersectional discriminations to enter and stay in the labour market.

²⁷ Source: National Disability Authority (NDA) 'Disability and Work: the Picture We Learn From Official Statistics' (Dublin: NDA, 2005) p 21. Available at: <http://nda.ie/nda-files/Disability-and-Work-The-picture-we-learn-from-official-statistics.pdf>.

²⁸ Reichen 1,30 Euro Stundenlohn für Menschen mit Behinderung?, MDR, 2020, <https://www.mdr.de/nachrichten/politik/gesellschaft/menschen-behinderung-werkstatt-stundenlohn-100.html>.

Extra disability-related costs

People with intellectual disabilities **face extra costs to have the same standard of living as people with no disability**. On the one hand, many of those costs originate from an inaccessible environment, from the absence of reasonable accommodation, the lack of universal design and universal conception. The latter are often invisible in accessibility discussions and measures. On the other hand, extra costs come from higher medical bills, rehabilitation measures, or for example the need for specialised nutrition or the use of more electricity to keep assistive devices working.

TYPES OF EXTRA COSTS OF LIVING	
Indirect costs	Direct costs
e.g reduced opportunities for earning, unemployment or because household members stop working to provide assistance and care	represent the additional spending on goods and services that are required for a person to participate in society, such as assistive devices, support or rehabilitation

These extra costs of disability can lower the standard of living of persons with disabilities, as well as increase their risk of poverty or social exclusion and is often exacerbated by:

- a **lack of income**;
- a **lack of decision-making power** within the household (allocation of resources);
- the **limited available information** of programmes and strategies to minimise costs;
- the **absence of public spending** e.g., on inclusive education and accessible infrastructure.

A research by the European Parliament from 2018 estimated that the additional costs faced by persons with disabilities to access goods and services in the EU combined amount to between 15-41 billion euros per year.²⁹

In Spain the main expenses that constitute the extra disability related costs are medical treatments (29%), medicine (28.3%) technical aids (28%), transport and mobility (24.3%) and personal assistance (21.6%).³⁰

²⁹ Report of the European Parliament Research Service, 2018.

³⁰ Special report by the Spanish National Disability Observatory, 2019, <https://drive.google.com/file/d/1mLyQEYD2Mlez8YXYdMX3e3huJcqMxGbc/view>

In Ireland the extra costs of a household involving a family member with a severe disability account to 23.7% of the household's income, for a family member with "some limitations" the average is estimated to account to 20.3% of the household income.³¹

In **Belgium**, 13.2% of respondents suffer from severe material deprivation, even if their income is above the poverty line. In total, 52.5% of them are at risk of poverty and/or suffer from severe material deprivation. These statistics can be explained by the additional cost persons with disabilities face, which also imply that people need to save on basic expenses in order to compensate for these additional costs.³²

In England living costs are on a monthly average 570 pounds higher for a person with a disability.

49% of persons with disabilities living in the England state that they had to take out a loan to meet their basic needs.

23% of households involving a member with a disability live below the poverty line.³³

These findings clearly show that persons with disabilities, even when receiving adequate pay, face more expenses, often due to an inaccessible society or medical treatment, and are consequently at higher risk of poverty and social exclusion. However, the extra disability related costs of disability are not considered in the current poverty measures at EU level.

→ This shows that the extra disability related cost must be incorporated into social policies poverty measurements.

→ There are three ways to measure the extra costs of living:

1. Standard of living approach (SOL)

³¹ Cullinan, J., Gannon, B. and Lyon, S. Estimating the Extra Cost of Living for People with Disabilities. Health Economics (2008).

³² Pauvreté et Handicap en Belgique, UNIA, 2019, https://www.unia.be/files/Documenten/Publicaties_docs/livre-pauvrete-et-handicap-en-belgique-2019-fr.pdf.

³³ Extra Costs, Scope, <https://blog.scope.org.uk/wp-content/uploads/2013/07/credit-and-debt1.pdf>.

Measures the underlying relationship between a standard of living indicator, income, and disability.

2. **Good and services and the expenditure approach**

Measures household budget and consumption and goods and services that are required to identify disability related extra costs of living.

3. **Direct subjective approach**

Asks persons with disabilities directly about which expenses and goods and services they require to participate fully in society, which also increases the participation of persons with disabilities.³⁴

Disability benefits

Disability benefits are a very important source of revenue to support people with disabilities, to cover their expenses and extra disability related costs. Therefore, disability benefits are a very effective social protection tool to prevent poverty. However, across the EU, disability benefits differ greatly, and it can be very difficult to fulfil the eligibility criteria to receive disability benefits, and even if so, it is unlikely that the benefits cover all the expenses of a person. This is mainly due to the great differences of **disability assessments** as well as **cuts in benefits** due to austerity measures.

Disability Assessments

Many countries still exclusively use a model based **on medical or functional indicators**, rather than taking into account environmental or social barriers. These kinds of assessments are not in line with the United Nations' Conventions on the Rights of People with Disabilities (UN CRPD)³⁵ and consequently often miss out people who need disability benefits to cover daily expenses and extra disability related costs.

Once people are granted benefits, it can take weeks to receive their first payment, during which people experience hardship to cover the most necessary goods.

³⁴ The extra costs associated with living with a disability in the United States, National Disability Institute, 2020 <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-working-paper.pdf>.

³⁵ Poverty and Social Exclusion of Persons with Disabilities, EDF, 2020.

In **England**, people with disabilities awaiting their benefit payment often have to rely on support from foodbanks, friends and family.³⁶

Until November 2020 alone, it is estimated that 50,000 people died waiting for their disability benefits in **Spain**. Adding up to 160 persons dying every day due to a 'bureaucratic labyrinth' to access their benefits.³⁷

Cuts in benefits

Cuts in benefits are often a result of austerity measures taken by governments, often disproportionality affecting people with disabilities. Research shows that several European countries have **continuously decreased disability benefits, pensions and support for assistive devices and community-based services.**³⁸

In **France**, the income of the partner or spouse is taken into account in the calculation of the disability benefits, which leads to people with disabilities losing their disability benefits, while still facing higher expenses.³⁹

Plus, in 2019 a law project aimed at merging minimum income with disability benefits.

Those are examples out of many, illustrating a common misconception of the disability benefits.⁴⁰

In 2017, **England** reassessed all disability benefits receivers, a process plagued with errors, disrespect and ignorance of health problems. One case highlighted how an assessor asked a person with down syndrome how they "caught" it. After the reassessment of all benefit

³⁶ Crippled, Austerity and the Demonisation of disabled people, Frances Ryan, 2019.

³⁷ Casi 50.000 personas han muerto esperando a las ayudas de dependencia este año, Servimedia, November 2020, <https://www.servimedia.es/noticias/1332626>.

³⁸ Assessing the impact of European governments' austerity plans on the rights of people with disabilities, ENIL, 2012, <http://enil.eu/wp-content/uploads/2012/12/Austerity2012.pdf>.

³⁹ Désolidarisation des revenus du conjoint pour le paiement de l'Allocation aux Adultes Handicapés, e-pétitions du Sénat, <https://petitions.senat.fr/initiatives/i-416>.

⁴⁰ Allocation Aux Adultes Handicapés (AAH) APF France handicap réagit au rapport de la Cour des comptes : l'AAH n'est pas un minimum social comme les autres !, APF France Handicap, 2019, https://www.apf-francehandicap.org/sites/default/files/cp_aah-courdescomptes-vdef.pdf?token=MT0qAyVB.

receivers was done almost half of the persons with disabilities had their benefits cut or reduced.⁴¹

Moreover, **disability benefits often diminish when a person finds employment**, which is commonly referred to as the “social benefit trap”. This can be very difficult, as a person may have an income, yet is still facing high expenses for extra disability related costs. Therefore, people who find a job can still experience **in-work poverty**.

Reduced purchasing power

While disability benefits are decreasing across Europe, **the prices of goods and services have increased** by 1.5%. While this is an average across Europe, prices have raised even more in certain countries; in Romania goods and services have increased by 3.9%, in Hungary by 4.4% and Slovakia 2.8%.⁴² Overall this has dire consequences for people with disabilities across the EU and negatively affects their ability to purchase goods and access services. Demonstrating the importance of social protection, for example through disability benefit allowance, to combat poverty.

On top of that, people with disabilities relying on disability benefits, often **do not qualify for high bank loans**, this can increase dependencies on family and friends and can impact the person’s living situation, wellbeing and dignity.

- ➔ Welfare benefits must continue to cover employed people with disabilities, as extra costs of disability will not disappear when in employment.
- ➔ This is also why disability assessments must be in line with the social model of the UN CRPD to leave no one behind.
- ➔ Disability benefits and social policies must factor in the extra disability related costs.

⁴¹ Crippled, Austerity and the Demonisation of disabled people, Frances Ryan, 2019.

⁴² Consumer prices – inflation, Eurostat, 2019, https://ec.europa.eu/eurostat/statistics-explained/index.php/Consumer_prices_-_inflation.

Unpaid care work

In 2017, **circa 5% of families in the EU involved a child with a disability**, of which many face higher financial constraints, higher levels of stress and more social isolation.

Parents with children that are in need of long-term care face additional barriers when community-based services are unavailable or not accessible, which often leads one parent to give up their job to take care of their child.⁴³

In the **European Union**, the risk of experiencing poverty and exclusion for those families is of 15.6% higher than compared to other households.⁴⁴

A study by the Equality and Human Rights Commission in 2017 revealed that having a family member with a disability can push a whole family in **England** into poverty. Almost six in ten families with a member with a disability are currently living without basic necessities, such as food and shelter.⁴⁵

Children with disabilities are also more likely to live in a **single parent household** than other children, of which more often the mother remains parenting and raising them, due to a higher separation rate among parents of a child with a disability. Single parents need support and care services for their children, to be able to work and sustain the family. Yet, if those services are not available in the community, they often need to stay home to take over the care of their child, which impacts their financial situation and fuels institutionalisation of children.

According to the gender equality and long-term care study by EIGE, **women are more affected by taking over the care role than men**. In 2019, 62% of people that provided informal long-term care to older people or people with disabilities in the EU were women.⁴⁶

Findings from 2018 affirm that the main reason for women's inactivity in the labour market was

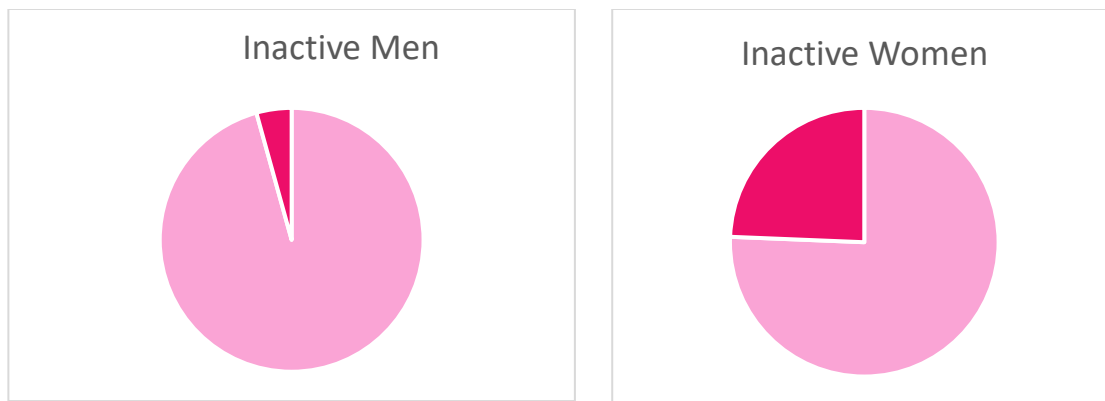
⁴³ Gender equality and long-term care at home, EIGE, 2020, <https://eige.europa.eu/publications/gender-equality-and-long-term-care-home>.

⁴⁴ Sustainable development in the European Union Monitoring report on progress towards the SDGs in an EU context, EUROSTAT, 2020, <https://ec.europa.eu/eurostat/web/products-statistical-books/-/ks-02-20-202>.

⁴⁵ Crippled, Austerity and the Demonisation of disabled people, Frances Ryan, 2019.

⁴⁶ Gender equality and long-term care at home, EIGE, 2020, <https://eige.europa.eu/publications/gender-equality-and-long-term-care-home>, <https://eige.europa.eu/publications/gender-equality-and-long-term-care-home>.

due to caring responsibilities, often because of a lack of available and accessible care services in their community. Out of the total amount of inactive women in the labour market, 42% stated that their caring responsibility was the main reason for them not to take part in the labour force.⁴⁷ This is very high, as in contrast only 4.5% of inactive men reported that caretaking was the reason for being inactive in the labour market. Thus, the gender gap (in favour of men) for inactivity because of caring responsibility in the EU was 27.7%.⁴⁸



In dark pink is the share of inactive people having care responsibilities. This clearly shows how women are more affected by caring responsibilities.

The gender gap in care work also becomes evident through the Work-Life Balance Eurobarometer (2018), which shows that across the EU:

- women spend **22 hours** a week in unpaid work;
- versus less than **10 hours** for men.

Additionally, 42 % of all women with desired part time contracts, claimed to have them to be able to take on unpaid care work. Unpaid care work can fuel in-work poverty.

But even those receiving benefits for their care work often do not receive enough money to cover all the necessary expenses.

In 2019, members of the **Croatian** disability organisation⁴⁹ protested, calling on Minister Vesna Bedekovic to improve the status of parents of caregivers and caregivers of children with

⁴⁷ Work-life balance Eurobarometer, 2018.

⁴⁸ Sustainable development in the European Union Monitoring report on progress towards the SDGs in an EU context, EUROSTAT, 2020, <https://ec.europa.eu/eurostat/web/products-statistical-books/-/ks-02-20-202>.

⁴⁹ The Association of Families of Children with Developmental Disabilities and Persons with Disabilities "Sjena".

disabilities, and to treat them legally as workers with pay and sick leave. Caregivers say their situation is unsustainable because the vast majority of them live in social isolation and on the brink of poverty, which puts them and their children with disabilities at risk.

"We warn that this [benefit] amount is too small, insufficient, and that no one in Croatia can live a quality life. We warn that we are socially excluded and live on the edge of poverty," said Rešetar. ⁵⁰

- The strategy to put the **Work-Life Balance Directive** into action must pay extra attention to persons with disabilities and their carers to prevent in-work poverty and poverty of households.
- Affordable and accessible community-services are vital to support families and their family members with disabilities, prevents in-work poverty and institutionalisation.

Shortage of professional home-based care

The shortage in available home-based care services becomes apparent when looking at statistics that reveal the low use of professional care across Europe, which is in Belgium with 10% the highest and merely above 1% in Estonia, Slovakia and Romania. Overall, only 15% of women and 9% of men said they were receiving professional home-based care. The recipient-social worker ratio is the highest in Sweden, Ireland and Denmark, the lowest in Estonia, Romania and Slovenia. On average there is 1 care worker for 20 adults.

Therefore, many people with disabilities have to rely on informal care provided by family and friends or by persons with no official care status, who do not receive an official salary.

Often, the needs of children with disabilities, especially those with complex support needs, are not met in terms of affordability, accessibility and quality by national long-term care systems, especially in rural areas where available nursing and social care resources are more limited.

⁵⁰ Hrvatski Zavod za Zapošljavanje (2020) Izvješće o aktivnostima hrvatskog zavoda za zapošljavanje u području zapošljavanja osoba s invaliditetom u razdoblju od 1. siječnja do 30. rujna 2020.

Consequently, the main type of care for children with disabilities is carried out through informal care by parents. Yet, many parents, especially single parents, face a higher risk of poverty or have financial difficulties to afford available care services. This often leads parents with no choice than bringing their child into residential care.⁵¹

In **the Netherlands**, extra support under the Youth Act can be provided only if their social networks are inadequate or the support is not falling under the 'usual care'. Then support may be provided individually, in a group or in a residence.⁵²

Currently data on whether children with disabilities receive the care they need is largely unavailable. Yet, available and affordable long-term care and support can prevent the institutionalisation of children with disabilities. While, the European Disability Strategy 2010-2020 does encourage deinstitutionalisation, it does not cover the challenges of long-term care for persons with disabilities as well as no gender focus.

⁵¹ Gender equality and long-term care at home, EIGE, 2020, <https://eige.europa.eu/publications/gender-equality-and-long-term-care-home>.

⁵² An international comparison of care for people with intellectual disabilities, The Netherlands Institute for Social Research, 2018.

Consequences of poverty

Barriers to inclusion and independence

Living in poverty has many consequences on the day-to-day life of persons with disabilities. It limits opportunities and choices to participate in society, in leisure activities and to live independently.

A pilot study from **Germany** revealed that a lack of financial resources constitutes one of the major barriers to persons with intellectual disabilities to participate in all aspects of society and moreover has reinforcing effects on many other barriers. The study shows that financial poverty can impede dependencies and constraints for persons with intellectual disabilities, as for example the budget available for food shopping is so limited, that it becomes too difficult to do one's own shopping independently. A woman stated that she had only a 40€ budget for her weekly grocery shopping, so she could only afford the bare minimum. **"A lack of financial resources becomes a massive barrier to participation in all aspects of life" and hinders inclusion** concludes the study.⁵³

Digital exclusion

EU Member States with higher levels of digitalisation have a significant reduction in poverty and social exclusion.⁵⁴ However, access to digital devices and connectivity remains a barrier for persons with disabilities.

Self-advocates from Europe affirmed that access to digital devices and connectivity remains a barrier for persons with disabilities. Amidst the Covid-19 pandemic, their main work was focused on providing isolated persons with intellectual disabilities with Wi-Fi connection and devices. This way people had a chance to stay in contact with their family and friends during the COVID-19 lockdown.⁵⁵

⁵³ Trescher, Hendrik: Kognitive Beeinträchtigung und Barrierefreiheit. Eine Pilotstudie. Bad Heilbrunn : Verlag Julius Klinkhardt 2018, 182 S. - (Klinkhardt forschung) - URN: urn:nbn:de:0111-pedocs-160438

⁵⁴ Journal of Risk and Financial Management, Digitalization of the EU Economies and People at Risk of Poverty or Social Exclusion, July 2020, https://www.researchgate.net/publication/342685086_Digitalization_of_the_EU_Economies_and_People_at_Risk_of_Poverty_or_Social_Exclusion.

⁵⁵ Information retrieved from Global Self-Advocacy Summit, Inclusion International, December 2020.

A study from **Poland** has shown that insufficient financial resources and a low socio-economic status, among other factors, are related to the digital divide among persons with disabilities and persons with no disabilities. The barriers to access to information are especially high for persons with intellectual disabilities.⁵⁶

Another study from **Germany** affirms that financial poverty impedes constraints of persons with intellectual disabilities to afford internet access or smartphones.⁵⁷

Energy poverty

Over the last years energy bills have been steadily rising across the EU, as companies are taking advantage of liberalisation measures to maximise their profit.

In 2010, the European Economic and Social Committee published an opinion on the effects of energy liberalisation on energy poverty. It revealed that the rise of energy prices added to low income and inadequate building quality, have been the drivers of **energy poverty**, impacting the health of people, as well as their quality of life.⁵⁸

This is particularly true for persons with disabilities, as they are more affected by poverty, are more dependent on electricity and often consume more electricity than people without disabilities, due to their dependence on assistive technologies (breathing devices, power wheelchairs), a tendency to spend more time at home, a generalised lack of access to adequate housing e.g., with good isolation.

Reports in **Spain** have shown that people with disabilities are more exposed to energy poverty, in particular people with intellectual disabilities due to difficulties in understanding the services they hire.⁵⁹

⁵⁶ Digital divide among people with disabilities: Analysis of data from a nationwide study for determinants of Internet use and activities performed online, Mariusz Duplaga, 2017, <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0179825>.

⁵⁷ Trescher, Hendrik: Kognitive Beeinträchtigung und Barrierefreiheit. Eine Pilotstudie. Bad Heilbrunn: Verlag Julius Klinkhardt 2018, 182 S. - (Klinkhardt forschung) - URN: urn:nbn:de:0111-pedocs-160438

⁵⁸ Energy poverty – the impact of liberalisation and the economic crisis, European Economic and Social Committee, 2015, <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/energy-poverty-impact-liberalisation-and-economic-crisis> .

⁵⁹ Estudio sobre los Consumidores vulnerables en el sector Eléctrico, Hipsa Coop, <https://www.hispacoop.com/home/index.php/energia/427-estudio-sobre-los-consumidores-vulnerables-en-el-sector-electrico>.

In 2017, a study from the **United Kingdom** revealed that one in six people with disabilities needed to live with a coat indoors, as they could not afford heating their house anymore.⁶⁰

Lack of affordable housing

The right to decent and affordable housing is a fundamental right enshrined in Article 16, 30 and 31 of the European Pillar of Social Rights and protects the health and wellbeing of individuals. Yet, finding decent and affordable housing has become increasingly difficult for persons with disabilities, 12.5% of people with disabilities spend more than 40% of their disposable income on housing, whereas only 9.9% of people without disabilities.⁶¹

Data shows that people with disabilities:

- Experience higher housing costs;
- Often live in worse housing conditions;
- Face higher housing overcrowding when over the age of 65.

The main reason for this is the **unaffordability** of accessible decent housing. As it is very costly to purchase a house that is accessible and people with disabilities relying on disability benefits or those placed under guardianship cannot take out loans at the bank. This often leaves people no other chance than borrowing from their family and friends, starting a crowdfunding campaign, or stay with their family or move to institutions.

A lack of affordable housing remains as one of the main causes for homelessness⁶² and leads to *de facto* housing segregation, which also leads to unequal access to services.⁶³

Poorer Health

⁶⁰ Joseph Rowntree Foundation, 2017.

⁶¹ Report on access to decent and affordable housing for all, European Parliament, 2020, https://www.europarl.europa.eu/doceo/document/A-9-2020-0247_EN.html.

⁶² Homelessness, European Commission, <https://ec.europa.eu/social/main.jsp?catId=1061&langId=en>.

⁶³ Strategic Dialogue on the EU Child Guarantee, EURO CITIES, 2020

Poverty also affects people with intellectual disabilities' access to health services when compared to people without disabilities. This is largely due to the extra costs deriving from:

- medical care,
- staff having little understanding about intellectual disabilities and thus often failing to diagnose and recognising that a person with intellectual disabilities is unwell,
- inadequate aftercare or follow-up care,
- the lack of accessible services.⁶⁴

Malnutrition

As persons with disabilities and households with a person with a disability are more likely to experience poverty, they tend to be disproportionately affected by an unequal distribution of resources that can impact their access to adequate nutrition. This becomes particularly worrying concerning those having dietary needs, a factor that can also contribute to poverty among the household.⁶⁵

In **England**, in 2017, one in five persons with disabilities were living in food poverty, which means persons needed to skip meals or lived without essential nutrients on a daily basis.⁶⁶

Institutionalisation

The absence of affordable and available community-based services for persons with intellectual disabilities often leads to family members taking over the informal care of a loved one. To do so family members often forgo full-time employment or employment at all, this coupled with inadequate support and the extra expenses faced to cover the disability related costs, can push whole families into poverty and hardship. According to recent research, the absence and unaffordability of community-based services and support is a key reason why children with intellectual disabilities tend to be disproportionately placed in institutions.⁶⁷

This clearly shows how quality care and available and affordable community-based services can prevent institutionalisation.

⁶⁴ Disability and Health, WHO, 2020, <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>.

⁶⁵ World Report on Disability, WHO, 2011, https://www.who.int/disabilities/world_report/2011/report/en/ .

⁶⁶ Crippled, Austerity and the Demonization of Disabled People, Frances Ryan, 2019.

⁶⁷ Gender equality and long-term care at home, EIGE, 2020, <https://eige.europa.eu/publications/gender-equality-and-long-term-care-home>.

The costs arising from disability are “extremely high, we pay for therapies, pay extra for aids, buy medicines for children. And the only answer we get over the years is always the same - 'you can place a child in an institution’”. Suzana Rešetar ⁶⁸

⁶⁸ Member of the Sjena association, Suzana Rešetar, <https://www.24sata.hr/news/prosvjed-roditelja-njegovatelja-zivotarimo-s-tek-2500-kuna-663205>.

EU actions towards ending poverty

Despite EU institutions' increasing efforts to address social rights, through the development of the European Pillars of Social Rights and a vast array of soft law establishing goals related to poverty and social exclusion, the EU is unable to properly resolve certain issues.

Reasons for that are:

- **The lack of harmonised definitions and indicators across the EU**

The definition of disability varies from country to country and because of these differences, entitlements of persons with disabilities to services vary across Europe and it may even hinder their access to quality services and further social exclusion and poverty.

According to Eurostat, the at-risk of poverty rate is measured through "the share of people with an equalised disposable income (after social transfers) below the at-risk poverty threshold", which measures the income of people. The at-risk of poverty rate before social transfers is "calculated based on the income of a persons before social transfers" and while it does recognise benefits as income,⁶⁹ both methods may be misleading. As persons with disabilities often face extra disability related costs, which are not reflected when only looking solely on the income to assess a person's risk of poverty.

- **The lack of disaggregated data**

Due to data not being broken down by type of disability, age and gender, it remains difficult to assess barriers unique to persons with intellectual disabilities. Moreover, persons living in collective households and institutions are excluded from Eurostat's data collection on poverty and employment.

Promising actions

The **EU Child Guarantee** is an upcoming opportunity to improve the quality of life of children with intellectual disabilities as it will focus on children in poverty and at risk of social exclusion.

⁶⁹ Income poverty statistics, Eurostat, 2020, https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Income_poverty_statistics&oldid=440992.

It will address children's access to five policy areas: early childhood education and care, healthcare, quality education, decent housing, nutrition and culture and leisure activities.

The upcoming **Action plan on the European Pillar of Social Rights** aims at ensuring that the Social Pillar reaches its targets, as it presents the opportunity to implement and realise the rights of persons with intellectual disabilities in all actions, policies and strategies of the European Pillar of Social Rights, such as gender equality, employment, youth and digitalisation.

The **Work-Life Balance Directive**, which aims at making it easier for caretakers to balance their work and caretaking responsibilities.

The upcoming **European Disability Strategy 2020-2030** holds the promise to fully implement the UN CRPD. Following the recent evaluation of the previous strategy, it must target poverty reduction, removing barriers for persons with intellectual disabilities and improve employment of persons with disabilities as well as target deinstitutionalisation.

Conclusion

This paper has highlighted how poverty presents a major barrier for persons with intellectual disabilities, in particular to women with disabilities, to inclusion, well-being and participation in society. The causes of poverty are manifold and rooted in structural discrimination and lack of awareness across Europe. Ranging from unemployment, in-work poverty, cuts in disability benefits or losing benefits, extra disability related costs, to unpaid care work and shortage of home-based care. While the European Union continuously aims at reducing poverty, people with disabilities were among the groups that benefited the least from poverty reduction policies over the last years. As a consequence of that, people with intellectual disabilities and their families:

- Cannot participate in society on equal grounds with others, which results into exclusion and isolation.
- Cannot take part in leisure activities.
- Face a higher risk of institutionalisation.
- Face digital exclusion and consequently more social isolation.
- Experience energy poverty.
- Live in inadequate and segregated housing or become more dependent due to a lack of affordable housing.
- Have poorer health and are often malnourished.

This shows how urgently targeted actions are needed to combat poverty, to increase wellbeing, the quality of life, end institutionalisation and achieve the full inclusion of persons with intellectual disabilities.

Recommendations

→ Disaggregated data

The collection of disaggregated data and in line with the UN CPRD is of the utmost importance, to inform evidence-based policies and demonstrate where specific and targeted support is needed.

→ Intersectionality

To combat poverty and discrimination of women with disabilities, extra attention in poverty reduction measures must be paid to women with disabilities across the EU. Therefore, the European Gender Equality Strategy and the EU Gender Action Plan must address the multiple and intersectional discrimination against women with intellectual disabilities e.g., in the labour market.

→ Employment

To increase the participation of people with intellectual disabilities in the labour market, the implementation of **job coaching** and **job carving** schemes and heavy investments in the transition from education to employment are needed. To specifically address unemployment barriers by persons with intellectual disabilities, data must be collected by type of disability and by gender, as well as include persons who are inactive, persons living in collective households, in institutions and work in sheltered workshops. Additionally, the workers and labour rights of people working in sheltered workshops must be recognised. Lastly, **targeted social and employment policies** must be developed to address unemployment rates of people with intellectual disabilities as well as the multiple and intersectional discriminations while finding employment and being employed.

→ Poverty measures

The extra disability related costs must be incorporated into poverty measures to adequately shed light on the situation of people with disabilities across Europe and develop targeted policies.

→ Disability benefits

Disability assessments across the EU must be in line with the social model of the UN CRPD. Moreover, it must be ensured that people with intellectual disabilities do not lose the disability benefits when they enter the open labour market. For this reason, it is equally important that disability **benefits and social policies incorporate the extra disability related costs to prevent reduced purchasing power and poverty** of benefit holders. Disability allowances are vital social protection measures to protect people from poverty.

→ **Caretakers**

To protect and support caretakers from in-work poverty and household poverty, the strategy to put the Work-Life Balance Directive into action must pay extra attention to persons with disabilities and their caretakers. To prevent the institutionalisation of people with intellectual disabilities families must receive adequate support and have access to affordable community-based services.