Briefing on discrimination and social exclusion of Roma with disabilities

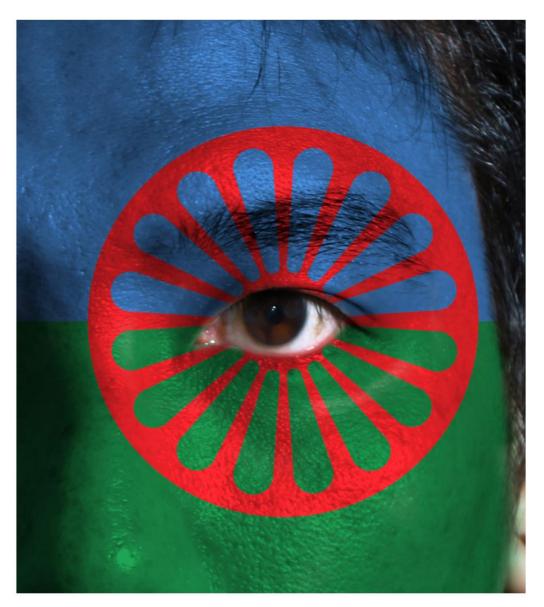


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Authors: Haydn Hammersley (EDF) and Marine Uldry (EDF)

Contributors: Amana Ferro (ERGO Network), Isabela Mihalache (ERGO

Network) and Elise Jacquier (EDF)

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Introduction

There is limited information on the situation of Roma¹ with disabilities in the European Union. In the disability movement and policies, the issues faced by Roma people are mostly unknown and unaddressed. This can be explained by the lack of data and research, but also intersectional discrimination and antigypsyism faced by Roma and Travellers across Europe. Persons with disabilities who are part of Roma communities also face additional barriers and marginalisation, that are not often talked about.

Available data and field experience show that there is a high prevalence of disabilities among Roma communities, also informed by the overall Roma health inequality gap and poorer state of health of the Roma population. Impaired access to healthcare and long-term care services means that many Roma do not receive adequate treatment for acute health conditions (going as far back as pre-natal care), which leads to these conditions becoming chronic over time and leading to early onset of disability.

This briefing aims to shed light on the discrimination and social exclusion faced by Roma with disabilities across Europe, using new data collected by the European Union Agency on Fundamental Rights (FRA) and research from the European Roma Grassroots Organisations (ERGO) Network.

It also provides recommendations to the EU on the measures needed to comprehensively address key issues faced by Roma with disabilities.

¹ The umbrella-term 'Roma' encompasses diverse groups, including Roma, Sinti, Kale, Romanichels, Boyash/Rudari, Ashkali, Egyptians, Yenish, Dom, Lom, Rom and Abdal, as well as Traveller populations (gens du voyage, Gypsies, Camminanti, etc.). <u>EU policy documents and discussions</u> commonly employ this terminology.

Data and Methodology

The data from this report is taken primarily from a <u>study conducted by the European Union Agency for Fundamental Rights, released in 2022</u>. In this paper, we refer to the Agency as the Fundamental Rights Agency or by its acronym, FRA. The data, collected in 2021, covers 10 European countries; 8 in the EU and 2 outside of the EU. These countries are Czechia, Greece, Spain, Croatia, Hungary, Italy, Portugal, Romania, Slovakia, Serbia and North Macedonia, countries with large Roma populations.

The aim of this paper is to extract the specific findings on Roma with disabilities. The data set used is disaggregated by differing levels of disability. It begins by showing data on Roma without disabilities. To this, we can compare and contrast data on Roma people who are "severely limited" or "limited but not severely". Since the notion of "limitation" is very much a product of the societal barriers a person with disabilities faces, and their need in some cases for support to navigate these barriers, we will instead refer to persons with "disabilities and high support needs" and "persons with moderate support needs" respectively.

This document does not present new data, but rather extracts and analyses data specific to Roma with disabilities to better expose the additional challenges that arise from intersectional discrimination, and the barriers linked both to being Roma and having a disability. We also explore the particular issues faced by young persons with disabilities in the Roma community across Europe. Unfortunately, the data on Roma persons with

disabilities was not available by gender, so we were not able to provide data on specific issues faced by Roma women or non-binary people with disabilities.

This data is complemented by research carried out by the European Roma Grassroots Organisations (ERGO) Network between April and September 2022 in the six EU countries (Bulgaria, Czech Republic, Hungary, Romania, Slovakia, Spain), combining desk research as well as field experience and direct interviews with Roma living in marginalised communities in these countries. The research report, launched in November 2022, deals with Roma access to healthcare and long-term care in the six countries and includes a specific section on Roma with disabilities.

Background on Roma with disabilities and EU policies

While there is no accurate and comprehensive data on the number of Roma with disabilities in Europe, a 2016 study estimates that 15% of the Roma population are persons with disabilities, meaning that there would be more than 1.6 million Roma with disabilities in the EU, the Western Balkans and Turkey.²

Roma with disabilities are particularly at risk of **intersectional and multiple discrimination**. As will be shown in this briefing, Roma with
disabilities experience even greater isolation, less access to services such

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² https://www.ecmi.de/fileadmin/redakteure/publications/pdf/ECMI_Study__8_final.pdf

as inclusive education, healthcare, and long-term care, and more severe poverty than other persons with disabilities and Roma without disabilities.

In addition to discrimination and marginalisation based on their disability, Roma with disabilities also face **antigypsyism** and **racial discrimination**³. These forms of discrimination are systemic and structural, meaning that they keep Roma with disabilities at the margin of society. They face additional barriers in comparison to persons with disabilities who are not Roma, and more generally, with persons with disabilities who are not racialised.

In addition, Roma people may also face **discrimination by association and perception,** for example when they are perceived as having a disability while it is not the case and discriminated against because of it. A concrete example of this is the placement of Roma children in segregated education for children with disabilities.⁴

The European Commission adopted a <u>2020-2030 EU Roma Strategic</u> <u>Framework on Equality, Inclusion and Participation</u>. It recommends that national strategies set out "targets and measures for specific groups (Roma children, women, young people, older Roma or those with disabilities, mobile EU citizens, non-EU nationals, stateless Roma) to reflect diversity among Roma, including gender-responsive and child/age-sensitive measures". However, there are no specific European measures that

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https://antigypsyism.eu/wp-content/uploads/2022/01/Antigypsyism-reference-paper-PRINT-11.07.2017.pdf

⁴ Numerous cases at the European Court of Human Rights have dealt with the fact that young people belonging to Roma communities have been placed in special classes and schools dedicated to children with disabilities. See for instance, <u>D.H. and Others v. Czech Republic (no. 57325/00) 13 November 2007 (Grand Chamber)</u> or Horváth and Kiss v. Hungary January 29, 2013.

efficiently look at the issues faced by Roma with disabilities, and faced by both the Roma and the disability community.

The <u>EU Strategy on the rights of persons with disabilities 2021-2030</u> also fails to address the issues of Roma with disabilities. There is only one general reference to Roma in the strategy, and no concrete actions to address multiple and intersectional discrimination.

The <u>Council Recommendation on Roma equality, inclusion and</u>
<u>participation</u> adopted in March 2021 is the only EU document that makes
concrete recommendations related to Roma with disabilities, in particular in
relation to access to mainstream educational activities and processes,
access to quality health care and access to community and family-based
services.

Discrimination and exclusion faced by Roma with disabilities



Education

Available data clearly underlines the barriers Roma people face when accessing and completing quality education. This same data also indicates the extent to which having a disability exposes Roma people to extra obstacles.

In the European countries surveyed by the Fundamental Rights Agency, 81% of Roma with some form of disability dropped out of education early. While we lack data on Roma people with high support needs, the data

suggests that for those with more moderate support needs, but who nevertheless have a disability, only 21% completed upper secondary education. It is also suggested that a mere 2% complete tertiary education, although the data source was too limited to give an entirely accurate figure.

Roma children and young people with disabilities are also shown to be more prone to hate-motivated bullying and harassment. 19% of Roman children surveyed in the European countries where data was collected by the Fundamental Rights Agency claimed to have been the target of bullying or harassment during the previous 12 months. For Roma people of school age who have a disability and high support needs, the percentage of those surveyed who had been the victim of bullying jumped to 27%. With more than a quarter of young Roma people with disabilities being the victim of bullying and harassment in educational settings, it is no wonder that so many drop out early and do not receive the qualifications that could open the door for better job opportunities.

Discrimination against young Roma with disabilities was shown not only to come from other students, but equally from the school administrations themselves. 18% of Roma learners with high support needs, their parents or guardians, reported feeling discriminated against because of being Roma when in contact with their school. Institutional discrimination towards Roma children has also manifested by wrongly diagnosing Roma as having mental disabilities and placing them as a result in schools for pupils with special educational needs (SEN).⁵ In some countries, the trend of falsely

⁵ The European Court of Human Rights found violation of the Convention of Human Rights with regards to the right to education of Roma children in the case of the Czech Republic, Croatia and Greece. In *DH. V the Czech Republic*, (13 November 2007), the Court found that between 1996 and 1999, the majority of children in special schools in the Czech Republic were of Roma origin. Roma children of average/above average intellect were often placed in those schools on the basis of psychological tests which were not adapted to people of their ethnic origin. The Court

diagnosing Roma children with developmental and learning disabilities leads to their being placed in segregated schools with reduced curricula, which also contributes to overall inequalities in educational outcomes between Roma and non-Roma children.



The barriers young Roma with disabilities face to completing education, pave the way quite logically for numerous difficulties in entering the labour market. In the countries surveyed by the Fundamental Rights Agency, only 48% of Roma without any disability aged 20 to 64 declared their main activity status as "paid work". By way of reference, the EU average employment rate is 75%, and for persons with disabilities, it is 50.8%⁶. This suggests that the correlation between being Roma and being unemployed is greater than that of being a non-Roma person with disabilities. If we then take the data available for Roma people with disabilities, the employment rates are startlingly low. Only 29% of Roma people with a disability and moderate support needs declared "paid work" as their main activity status.

concluded that the law at that time had a disproportionately prejudicial effect on Roma children, in violation of the prohibition of discrimination, the right to education. In Oršuš and Others v. Croatia (16 March 2010), the Court observed that only Roma children had been placed in the special classes in the schools concerned. The Croatian Government attributed the separation to the pupils' lack of proficiency in Croatian; however, the tests determining their placement in such classes did not focus specifically on language skills, the educational programme subsequently followed did not target language problems and the children's progress was not clearly monitored. The placement of the applicants in Roma-only classes had therefore been unjustified, and amounted to discrimination under the Convention. Similar judgements were given in Sampanis and Others v. Greece, judgment of 5 June 2008; Horvàth and Vadàzi v. Hungary, decision on the admissibility of 9 November 2010; Sampani and Others v. Greece, judgment of 11 December 2012; Horváth et Kiss c. Hongrie, judgment of 29 January 2013; Lavida and Others v. Greece, judgment of 28 May 2013.

⁶ Check progress on the Strategy for the Rights of Persons with Disabilities - Employment, Social Affairs & Inclusion -European Commission (europa.eu)

For Roma people with disabilities and high support needs, the figure was no more than 11%.

Young Roma people with disabilities have to contend with an additional barrier to employment on the basis of their age. The data available indicates that 63% of Roma people aged 16-24 with a disability entailing low support needs, were neither in education, employment or training. For Roma people of the same age but with high support needs, an astounding 84% are neither in education nor in occupying any professional or vocational role. These figures paint a bleak picture of life as a young Roma person with disabilities, whereby the vast majority are involved in no professional or educational activity whatsoever.

Many respondents claimed to have felt discriminated against when looking for a job, largely because of being Roma. 33% of Roma with disabilities and only moderate support needs found this to be the case, and 37% of Roma people with high support needs. ERGO Network stresses that discrimination doesn't stop at recruitment but also persists in the workplace, as many employers, other employees, customers, and partners lack the necessary cultural awareness and inclusive communication skills to deal in a sensitive way with people with a disability and / or of a different ethnic background. The insufficiency of support systems for including people with disabilities in the labour market – such as workplace adaptations, flexible schedules, an inclusive culture etc. – leads to Roma workers and jobseekers being doubly penalised.



In part linked to the difficulty in accessing the labour market, although by no means exclusively, Roma communities face a much higher risk of poverty and social exclusion. In the 10 European countries studied by the Fundamental Rights Agency, 79% of Roma people covered by the data were shown to be at risk of poverty. For Roma people with disabilities entailing moderate support needs, 82% were deemed to be at risk of poverty. For those with high support needs, the proportion jumps to 90%. In other words, if you are a Roma person with high support needs linked to your disability, it is significantly more likely that you will be living below the poverty line than above it.

The figures show a similar trend for those shown to have "great difficulties making ends meet". This was the case for 55% of Roma without a disability, 70% of Roma people with moderate support needs linked to a disability, and 82% of Roma people with a disability and high support needs.

Other data collected sheds light on what exactly it can mean to live below the poverty line. For example, if we take again the figures for Roma people with disabilities and high support needs, 62% of those surveyed were experiencing severe material deprivation⁸. 44% of people from this group could not afford a meal with meat, chicken, fish or a vegetarian option, every second day. 47% of such respondents were living in a household where one person had gone to bed hungry in the past month because there

⁷ Below 60% of median equivalised income after social transfers

⁸ Cannot afford four out of 9 selected items, e.g. food, inviting friends.

was not enough money for food. 70% of Roma people with high support needs linked to a disability did not even have a bank account.

As described above, this high poverty rate may be due to a variety of factors, from reduced access to education and lower access to employment, but also unequal access to social protection. ERGO Network also highlighted that Roma with disabilities face issues in receiving disability allowances, given a tendency to underestimate the degree of disability for adults in official certifications, not least due to antigypsyism, which in turn impacts the amount of social assistance received. The Roma also face other significant barriers to access adequate disability benefits, including not having access to diagnosis, financial costs, lack of information, poor transport links, and complicated application procedures.⁹



Access to healthcare

The marginalisation faced by Roma people with disabilities is no different in accessing healthcare services.

While the data collected by the Fundamental Rights Agency shows that Roma with disabilities with high or moderate support needs in the country surveyed are more likely to have medical insurance coverage, ¹⁰ it also reveals that they are less likely to perceive themselves in 'good' or 'very

⁹ ERGO Network's research report on Roma access to healthcare and long-term care, November 2022

¹⁰ In the 12 countries surveyed, 80% of Roma with disabilities with high support needs and 77% of Roma with disabilities with moderate support needs over 16 years old declared having medical insurance coverage, comparing to 76% of Roma without disabilities.

good' health and more likely to have felt discriminated against because of being Roma when accessing health services.

Figures reveal that only 21% of Roma with disabilities with moderate support needs perceived themselves in good health compared to 87% of Roma without disabilities.

Equally striking is the fact that Roma with disabilities in the 10 countries surveyed have felt discriminated against at a higher rate in accessing healthcare because of being Roma, when they also had a disability. The data show that 18% of Roma with disabilities with moderate support needs and 17% of Roma with disabilities with high support needs felt discriminated against, compared to 12% of Roma without disabilities. This reveals that antigypsyism may intensify for those with disabilities.

The available FRA data also show that more Roma women (16%) experienced discrimination when accessing healthcare than Roma men (13%). This may also be the case for women with disabilities in general, as they report higher unmet needs for healthcare under the <u>Gender Equality Index</u>. We can thus assume that there is also higher discrimination against Roma women with disabilities. There are concerns about human rights violations, such as forced contraception, forced abortion and forced sterilisation, as well as structural issues in accessing gynecological services which are still a reality in both the disability and Roma communities.

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¹¹ The <u>2022 Gender Equality Index</u> of the European Institute on Gender Equality reveals that, in the EU average, 9% of women with disabilities have unmet needs for medical examination (comparing to 8% of men with disabilities, 3% of women without disabilities and 2% of men without disabilities). 20% of women with disabilities perceived themselves in good or very good health, comparing to 23% of men with disabilities, 83% of women without disabilities and 85% of men without disabilities.

It is important to highlight that discrimination in accessing healthcare directly impacts the health status of the person, including their life expectancy and mortality rate. Roma populations have a markedly lower life expectancy than the general population in Europe. The FRA survey reveals that on average Roma women live 11 years less than men in the general population.¹²

ERGO Network's research also indicates that the Roma experience a poorer state of health than the majority population, with higher prevalence of chronic illnesses and lower life expectancy. At the same time, the Roma are not able to access healthcare and long-term care services on equal footing with the majority population, because of entrenched social determinants of health, limited coverage of health insurance, the absence of medical infrastructure and of qualified personnel (particularly in remote and rural areas), high costs of consultations and treatments, and lack of information and knowledge about healthcare and medical entitlements. A powerful deterrent is a non-inclusive, alienating healthcare and long-term care environment and discriminatory attitudes, either on purpose on account of widespread antigypsyism or involuntary due to insufficient antibias training and cultural awareness.

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¹² Life expectancy estimates at birth in 2017 was 11 years difference for Roma women and 9.1 years for Roma men.



Housing and independent living

While the absence of data on persons living in institutional care prevents us from being able to report very accurately on the number of Roma persons with disabilities confined to institutions, what limited information we are able to obtain indicates that both persons with disabilities and Roma people are disproportionately overrepresented within these settings¹³. This may be because there is a lack of comprehensive approach towards supporting independent living in the countries where Roma with disabilities live, but also because when it exists, Roma people do not seem to benefit from it.¹⁴ There is shown to be insufficient (if any) respite care facilities or availability of in-home support in remote and rural areas, such as those where most Roma settlements are located. Furthermore, lack of knowledge on entitlements, complex procedures, and high costs, among other things, present significant barriers to gaining support for independent living. At the same time, studies conducted by the European Roma Grassroots Organisations Network also point to an express preference of the Roma to care for people with disabilities at home, not least because of ill-treatment in facilities and their generalised distrust of facilities that don't understand their needs.

What the data can show us, however, are the living conditions of Roma people with disabilities living in the community, which can shed light on why some families might be turning to institutions as a last resort.

¹³ https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf

¹⁴ ERGO Network's research report on Roma access to healthcare and long-term care, November 2022

Figures show that 55% of Roma people with a disability and moderate support needs live in housing deprivation. "Housing deprivation" can be defined as living in an apartment that is too dark or has a leaking roof or does not have a bath, shower or indoor toilet, for example. For Roma people with a disability and high support needs, 59% experience such deprivation.

Overcrowding is also very prevalent, but on a similar level as for Roma people without disabilities. Here, around 75% of Roma people were shown to be living in overcrowded housing.

Beyond this, the question of basic sanitation is also a significant issue. This was something that caused even greater issues during the COVID-19 pandemic, where access to clean running water was essential to reduce the risk of infection. The problem of basic sanitation appears to be more present among Roma people with disabilities than among Roma people without disabilities. 18% of Roma people without disabilities live in households without tap water inside the dwelling, and 25% do not have a toilet, shower or bathroom inside their dwellings. For Roma people with disabilities and moderate support needs, these figures are 23% and 32% respectively. For Roma people with disabilities and high support needs, the figures jump again to 28% and 35% respectively.

Many Roma people with disabilities are shown to be living in dwellings with problems such as a leaking roof, damp walls, floors or foundation, or rot in window frames or floors. While this was the case for 21% of Roma people without disabilities, 32% of those with disabilities and moderate support needs experience such issues in their homes. The figure rises to 36% for Roma people with high support needs.

It is a similar story when it comes to the environment where these dwellings are located and, again, having a disability seems to only increase the likelihood of experiencing such a problem. The proportion of Roma people faced with pollution, grime, or other environmental problems in the local area, such as smoke, dust, unpleasant smells or polluted water was shown to be 21% for Roma people without disabilities, 25% for those with a disability and moderate support needs, and 27% for those with high support needs linked to a disability, figures that reflect a reality in which some Roma settlements are located directly on landfill sites.

Discrimination when looking for other more suitable dwellings was also clearly shown to be an issue. In this case, however, it appears to be Roma people without disabilities who face greater problems in being given access to better housing, with 27% claiming to have been discriminated against because of being Roma when looking for housing in the past 5 years. Insecurity of tenure, inability to pay rent or prove ownership, combined with the issue of forced evictions, leads to some Roma lacking a legal address which in turn affects their ability to seek care or apply for support in the form of disability allowance, among other things.

Conclusions and recommendations

The analysis of the data collected by the FRA confirms the research conducted by ERGO Network and the concerns of the European Disability Forum about the intersectional discrimination and marginalisation faced by Roma with disabilities in Europe.

Below we highlight the key findings from the FRA survey:

- Education: 81% of Roma persons with some form of disability dropped out of education early. Only 2% graduate from tertiary education.
- Employment: Only 29% of Roma people with a disability and moderate support needs declared "paid work" as their main activity status. For Roma people with disabilities and high support needs, the figure was no more than 11%.
- Poverty: For Roma people with disabilities entailing moderate support needs, 82% were deemed to be at risk of poverty, and 90% of those with high support needs.
- Health: 18% of Roma with disabilities with moderate support needs and 17% of Roma with disabilities with high support needs felt discriminated against in accessing healthcare (because of antigypsyism), compared to 12% of Roma without disabilities.
- Housing: 55% of Roma people with a disability and moderate support needs live in housing deprivation. There is no information about people living in institutions.

While some issues could be solved by separate Roma and disability inclusion policies, in other cases Roma with disabilities fall into gaps. This is why it is so important that the EU and Member States adopt targeted actions in the areas covered by this briefing.

We recommend to:

- Increase the visibility of Roma with disabilities and address
 policy gaps at European and national levels, including in the
 implementation of the EU Roma Strategic Framework and the EU
 Strategy on the Rights of Persons with Disabilities.
- Adopt a comprehensive horizontal EU equality law (directive), prohibiting inter alia, intersectional and multiple forms of discrimination in all areas of life, including at EU level by adopting a horizontal equal treatment directive. While Roma, as an ethnic group, can seek protection against discrimination under the Racial Equality Directive, Roma people with disabilities can only opt for protection on one or the other ground, i.e. either on ethnic discrimination or on disability, separately, having in mind that people with disabilities are only protected against discrimination under EU law in the field of employment. The current EU discrimination law leaves people with intersecting protected characteristics with limited protection and legal remedies.
- Start collecting equality disaggregated data, including by ethnic background, on people living in institutions in the EU and on the situation of Roma children with disabilities in foster care.
 Persons with disabilities and Roma people are disproportionately represented in these care settings, often deprived of their basic

- rights. As it stands, we cannot even present a clear number of the people who are currently institutionalised, nor understand clearly who they are and where/how they live. Roma children with disabilities are also over-represented and have lower rate of adoption.
- Increase the amount of spending that goes towards supporting Roma children with disabilities in mainstream education, and offer training and orientation to assist them in navigating the transition to the open labour market.¹⁵ In addition, train managers and personnel of care centers on diversity and anti-bias in order to improve knowledge, behavior and decision about and in their relations with people with disabilities from a diverse of minority background.
- Make use of EU funds, including the Recovery and Resilience facility, and urge Member States to invest their own national budgets in (accessible) housing first initiatives to give Roma people, particularly Roma with disabilities, the opportunity to move into better quality housing in the community. Monitor the misuse of EU funds, based on the fundamental rights conditionality, including discrimination based on disability, as relevant.
- Invest in targeted outreach measures to improve access to healthcare and long-term care services by Roma with disabilities, including by increasing access in rural and remote areas, combating antigypsyism, training professionals and ensuring the accessibility and affordability of the healthcare system and

¹⁵ Beyond Roma children with disabilities, the EU and Member States should also address the over-representation of Roma children without disabilities in segregated education. Roma children without disabilities are often referred to "special schools for children with disabilities" facing thus discrimination by assimilation.

services. This must also include banning and sanctioning human rights violations such as forced treatment, forced abortion, forced contraception and forced sterilisation, at the EU and national levels. We also recommend **supporting Roma health mediators**¹⁶ **and expanding their portfolio** to include better support for Roma with disabilities, as they play a key positive role bridging cultural and administrative divides between Roma communities and social services including healthcare and long-term care.

- Combat segregation of Roma with disabilities (including children) in segregated settings, by starting a de-institutionalisation process through conditioning the allocation or disbursement of EU funds (based on anti-discrimination and disability criteria) and by investing in community and family-based services, including equal access to disability assessment and allowance by Roma with disabilities.
- Involve Roma with disabilities and their civil society
 organisations in the design, implementation, and monitoring of
 policies that affect them, in order to increase ownership and inform
 evidence-based solutions through a bottom-up, partnership approach.

¹⁶ In many communities, Roma health mediators are employed to bridge cultural and communication gaps between services and residents (education mediators also exist for their related field). These mediators are typically Roma residents themselves, who speak Romani, and who are more easily able to gain the trust of the community and support people in navigating the system, as well as to relay their specific needs to healthcare and long-term care providers and raise awareness of cultural differences. Find more information in ERGO Network's research report on Roma access to healthcare and long-term care,

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November 2022.