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Translating disability towards social justice: Turning representations of persons with disabilities upside DOWN

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Abstract

Disability activism, together with social, gender, and racial justice struggles, has gained increased visibility in both civil society and academia. As a translation scholar and as the mother of an 11-year-old boy with Down syndrome engaged in promoting social justice, I strive to challenge the predominant representations of persons with disabilities that prevent them from exercising their human rights. This article proposes to build on the interdisciplinary intersections between feminist disability studies and critical translation studies, including audiovisual translation and media accessibility. It does so with a view to accounting for and contributing to inclusive practices in the translation of disability; it does so also to challenge ableist re-translation in a world where much remains to be done to protect the human rights of people with disabilities. The article analyses the political translation of disability in a video campaign carried out by the National Coordination of Associations of Persons with Down Syndrome (CoorDown). Released on the 2021 World Down Syndrome Day, the video titled *Dear Future Mom* is a collective response to an expectant mother of a child with Down syndrome who wrote to Coordown to share her uncertainties and fears following the diagnosis of Down syndrome. Including multiple languages and featuring children with Down syndrome as the main protagonists, *Dear Future Mom* creates a translational political space where the binary oppositions between non-disabled and disabled people are subverted. The video performs a political translation of the “original” textual body of children and young adults with disabilities that frames disability as compatible with a fulfilled life. The social model of disability that informs this political translation is challenged by the social and legal controversies surrounding the reception of the video. In criticizing the medical model of disability and its conflation of “defective bodies” with defective lives, this article alerts readers to the human rights consequences of this model for persons with disabilities and calls for alternative political translations that align themselves with disability activism and social justice struggles.

Keywords: political translation, disability, human rights, identity, ableism, Down syndrome

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1. Introduction

Translation is now increasingly understood as being a social and human practice which includes but extends beyond interlingual translation. Closely linked to identity issues and human rights, translation, and particularly self-translation, constitutes a tool of identity construction, as the practices of migrant artists have attested to (Bachmann-Medick, 2018; Di Maio, 2021; Inghilleri & Polezzi, 2020; Meng & Laviosa, 2020; Taviano, 2023). In an all-encompassing sense, translation operates linguistic, cultural, and social crossings that contribute to new meanings of and shifts in social identities (Spurlin, 2017). Given the social and cultural agency of translators (Baker, 2006; Gill & Guzmán, 2014) and the political engagement of activist translators and interpreters in contexts of intercultural mediation (Inghilleri, 2017; Taronna, 2015; Taviano, 2019), translation can be regarded as constituting a political practice (Doerr, 2018).

As a translation scholar, a mother of an 11-year-old boy with Down syndrome, and the president of Treali Onlus, an association and a centre offering rehabilitation to children with genetic disorders, I have recently become interested in approaching disability through a translation lens. Such an interdisciplinary exploration can harness the potential of recent intersections between translation and disability studies. Scholars from these two disciplines have started to intersect in several areas, as Spiśiaková (2021) reminds us. These areas include sign language interpreting (Díaz-Cintas et al., 2007), the language of disability, and the translation of legal documents regarding disability, such as the 2006 UN Convention on the Rights of Persons with Disabilities (Magris, 2018). The feminist strand of disability studies (Garland-Thomson, 2005; Hall, 2011) is particularly relevant in this regard as it casts light onto the social nature of mainstream representations of and assumptions about disability. People with disabilities – and their bodies – are marked as subordinate by exclusionary representations of disability in the same way as people belonging to other social categories are stigmatized because of their race and/or gender.

This article draws on two strands of research: first, translation studies' critical approach to the politics of translation, including the approach of audiovisual translation studies to media accessibility as social justice (Di Giovanni, 2020; Greco & Romero-Fresco, 2023; Matamala & Orero, 2018); second, the focus of feminist disability studies on the social processes of identity formation. Aiming to account for the activist nature of the translation of disability, this article draws on Doerr's (2018) concept of *political translation* and examines a video, titled *Dear Future Mom*, its reception and its subsequent censorship in France. This video was produced by CoorDown, the Italian National Coordination of Associations of Persons with Down Syndrome, for the 2021 World Down Syndrome Day. The video, featuring people with Down syndrome as the protagonists, is a fascinating example of political translation which challenges discriminatory representations of persons with disabilities and testifies to the fact that they can and should have the same rights as everyone else.

This is an important case of human rights translation since representations of disability, and of persons with disabilities' bodies, are culturally and socially located, and their translation across locations can either enable or prevent the rights of persons with disabilities being exercised. The way in which people are socially and politically categorized impinges on their rights, as is attested to by the violations of displaced people's human rights (Federici, 2020; Taviano, 2019, 2020). Drawing on Butler's (1999) claim that it is impossible to separate gender from culture and politics, Spurlin (2017, p. 173) contends that translation, as a site of struggle over social and cultural meanings, can contribute to exposing the myth of the "original" textual body. Translation therefore constitutes a political practice. As we shall see, CoorDown's video *Dear Future Mom* exposes the myth of the "original" textual body of children and young adults with disabilities and constitutes a "political translation" (Doerr, 2018) towards social justice.

2. Political translation of disability towards social justice

In the transnational and transcultural world in which we live, translation practice and theory have become vital in many areas. Migration is a real-life example of the critical role that translation, in its different modalities, plays in confronting and counteracting discrimination and social inequalities (see Inghilleri, 2017; Inghilleri & Polezzi, 2020; Taviano, 2023, 2025). In and beyond migration, translators – across categories of professionals, volunteers, and activists – take on a contentious political role, be it in conflicts (Baker, 2006), social movements (Baker, 2013; Boéri, 2022; Doerr, 2018), the humanitarian sector (Piróth & Baker, 2020) or the cultural industry (Pérez-González, 2016). Translators, interpreters, subtitlers, and mediators often organize themselves in activist communities and networks (Baker, 2009; Boéri, 2023a; Pérez-González, 2010), acting as activists and agents of political action and resistance.

In this light, contemporary translation studies increasingly account for the ways in which global struggles rely on translation, interpreting, and intercultural mediation across language, cultural, and systemic barriers. In encountering and having to deal with social oppression and discriminatory discourses against ethnic, gender, and linguistic minorities, critical translation and interpreting studies call for acting upon the ethical dilemmas of our time to advance social justice (see Boéri, 2023b). Such action reframes cross-cultural encounters as sites where social issues can be dealt with and resistance championed both at national and international levels (Spurlin, 2017). A critical translation approach can therefore shed light on the political importance of translation agents' practices in achieving social justice. In her book *Political Translation: How Social Movement Democracies Survive*, Doerr (2018) conceptualizes "political translation" as being beyond interlinguistic translation, extending it to "a disruptive and communicative practice … to address the inequities that hinder democratic deliberation, and to entreat powerful groups to work more inclusively with disempowered ones" (Doerr, 2018, p. 1). She shows how activist translators who intervene actively in local authorities' public meetings and in social movements' deliberative assemblies play a political role in redressing inequalities and problematic facilitation behaviours which impinge on the democratic participation of those who are most marginalized for intersecting gender, racial, and generational reasons. Doerr (2018) extends translation beyond cross-language intermediaries to any activist citizen who endorses an intermediary role. Citizens can also endorse a political function by challenging iniquities in a variety of social and political contexts and through different communicative and mediation practices. Citizens' activist translation is also particularly visible in self-translation, where common people can have a voice and become visible as makers of their own identity both within and across language and cultural boundaries. Indeed, a critical translation approach to migration can be extended to disability, as it shows that "acts of translation and self-translation have the potential to bear witness not just to the experience of the migrant [and the disabled] but also to our understanding of being 'human'", as Polezzi (2012, p. 356) rightly claims (see also Taviano, 2019).

This means that persons with disabilities, rather than being the object of translation, can translate themselves and become activists in the deconstruction of the myth of the "normal" body which is inherent to the ableist rhetoric. This is particularly important from a feminist disability studies perspective. Aiming to challenge "a system of exclusions that stigmatizes human differences" (Garland-Thomson, 2005, p. 1557), Garland-Thomson (2005) reminds us that "disability is a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate" (p. 1557). Bearing this in mind, there is a need to give voice to persons with disabilities and to promote the recognition of their rights actively across languages and cultures.

The active participation of persons with disabilities in audiovisual productions that are accessible to all in society strikes at the heart of recent developments in media accessibility. Traditionally situated in the domain of audiovisual translation, media accessibility focuses on the production and analysis of accessible media products such as films and documentaries. Whereas accessibility was traditionally intended for specific groups, usually persons with disabilities, it has now extended to all individuals in society. This overarching conceptualization of access intersects with translation practices. Indeed, dubbing, subtitling, and audio-description all render audiovisual products accessible to speakers of different languages and with sensory impairments (see Di Giovanni, 2020; Romero-Fresco, 2019). More importantly, the recent adoption of a user-centred approach to audiovisual products requires that accessibility should inform the (audiovisual) production process from the outset rather than being relegated to a mere post-production issue.

The accessibility turn in media design is particularly important from the perspective of feminist disability studies, because it allows the exclusion of minorities from audiovisual media to be countered. Indeed, persons with disabilities may be excluded from audiovisual media in their "participation, representation and fruition" (Greco & Romero-Fresco, 2023, p. 5): it is common knowledge among film viewers that there are few artists with disabilities among cinema actors, which means that persons with disabilities are rarely involved in the representation of disability. The percentage of actors with disabilities is as low as 2.5% in the United States (see Smith et al., 2017); and whenever films and series are concerned with disability, they mostly portray it through stereotypes or as a source of inspiration for non-disabled people. Finally, the coming to fruition of audiovisual products by people with disabilities can be impeded by multiple barriers (language, sensory, etc.). To resolve this problem, Greco and Romero-Fresco advocate creative and proactive media accessibility practices and a stronger engagement with diversity, not only by "debunking oppressive forms of accessibility", but also "by accepting that the question of access concerns all" (Greco & Romero-Fresco, 2023, p. 7).

The key insights to be gained from media accessibility and feminist disability studies can be harnessed in order to explore and examine how disability is the result of interactions between persons with disabilities and their social and cultural contexts, and how the representation of disability rests on the "political translation" of these interactions. Because *Dear Future Mom* places persons with disabilities at centre stage and encourages the viewing of disability as a human condition that concerns us all, it produces a compelling translational political space where binary oppositions between non-disabled and disabled people are subverted across language and sensory barriers.

3. Analysis of *Dear Future Mom*

Dear Future Mom was produced by CoorDown, the Italian National Coordination of Associations of Persons with Down Syndrome, for the 2021 World Down Syndrome Day. Its production involved the participation of children, young adults, and mothers from different associations. In this it collaborated with Singing Hands, a company that helps children to develop communication skills through music, songs, games, and gestures based on British Sign Language. As the title indicates, the video is directed at able-bodied women expecting a child diagnosed with Down syndrome. More broadly, it is also addressed to the global able-bodied community. The video conveys a heartwarming message: that people with Down syndrome can live full and enriching lives. It presents its message in several languages, including Italian, British English, Spanish, and Basque, which are at times accompanied by sign language and body language. In the following section I discuss the video's translational nature, its concluding claims and the "political translation" of disability it produces.

3.1 Translational and multilingual nature of the video

The video begins with an email written by a pregnant woman. "I'm expecting a baby. I've discovered he has Down syndrome. I'm scared: what kind of life will my child have?" The video continues with the following rewritten claim: "Today we reply to her like this", followed by fifteen children and young adults with Down's syndrome from different nationalities speaking different languages. They address future mothers with encouraging words to reassure them, and all of us, that their children, thus future adults, will be able to do many things: they will be able to hug them, run towards them and tell them that they love them. They will go to school like everybody else, will learn how to write to their mothers since they might be far away while they travel, and they will have a job, invite them to dinner as well as rent an apartment.

The translational nature of the video is evident in different ways. The video starts with a mother's questions in capital letters to clearly express her doubts and fears, shared by most, if not all, parents expecting and having children with disabilities. The answers are multimodally provided, that is to say, not only in different languages, but also through sign language and body language. More precisely, when the protagonists argue that children with Down syndrome will be able to hug their mothers, run towards them, and, above all, be happy, together with their mothers, all these messages are translated at various levels. First, they are expressed in the language of the child or the young person speaking, then they are subtitled into English to make their words accessible to a larger audience of spectators beyond those speaking that language and, finally, through Italian sign language.

The coexistence of several languages, including minority languages, emphasizes the plurality of people with Down syndrome, as with all persons with disabilities. The latter, who are often "on display or socially and politically erased" (Garland-Thomson, 2002, p. 56), here become protagonists. They acquire agency as self-translators and social actors and shape spaces of resistance through cross-language communication, something often ignored in monolingual narratives. They can translate who they are and what they are capable of doing as opposed to having others speak for them – that is, translating their experience through the lenses of ableism and being identified on the basis of what they cannot do.

Another instance of multiple translations is when, for instance, the claim is made that being the mother of a child with Down syndrome will sometimes be "difficult". One child says it in Italian for the first time, another girl repeats it and reinforces this notion by saying in Basque that it will be "ia ezinezkoa" (almost impossible), a boy repeats it in Italian – "quasi impossibile" (almost impossible)— and, finally, another young boy asks in French: "mais c'est pas pareil pour toutes le mères?" (but isn't it the same for all mothers?). The fear of being the mother of a person with Down syndrome, therefore with a disability, is sought to be dispelled not only by addressing an audience across languages and cultures, but also by making the difficulties of raising a child a joint human concern, whether the child is disabled or not. Here, the protagonists encourage expectant mothers of children with their syndrome to overcome social prejudices and recognize those universal elements of the parenting experience across disabled and non-disabled bodies and families: never-ending love, problems, and difficulties. The subversive role of these people's self-translating their experiences powerfully disrupts normative ideas of "normal" bodies and identities. This role challenges not only predominant images of disability, but even socially accepted notions of happiness. In fact, it must be said that the children and the young adults in the video follow a script prepared by a copywriter, but they nevertheless report the ideas and contributions of persons with Down syndrome and their families and members of associations belonging to CoorDown who have all contributed to the drafting and final editing of the script itself.

The address "Dear Future Mom" is repeated throughout the video, and so is the message of the very possibility of happiness of both the children with Down syndrome and their mothers. Children protagonists claim that persons with Down syndrome can be happy, "like I am", and extend this claim to expectant mothers together by saying "you'll be happy too". This message is expressed in spoken and signed languages, as one child produces the sign "happiness" on screen. It is also embodied in the protagonists, as children are seen hugging their mothers to convey and translate their happiness at yet another level, well beyond languages and words. Their mothers, in fact, do not articulate a verbal answer to the question "vero mamma?" ("is it true, mum?"). They simply hug their children back and express their mutual happiness, translating once again their feelings of a fulfilled life through their body language. Above all, they convey and translate the social significance of a child's happiness, which, rather than being viewed in isolation, is closely connected with and inseparable from that of their parents and family, and also society at large, as is illustrated below.

3.2 Concluding claims of the video: articulating various models of disabilities

The video concludes with three claims that are displayed in writing on the screen: “People with Down syndrome can live a happy life. Together we can make it possible. Everyone has the right to be happy.” These claims start with expressing the lived experience of happiness and then focus on the importance of a joint societal responsibility to individual happiness, which is closely related and leads to the advancement of human rights.

The first concluding claim of the video – “People with Down syndrome can live a happy life” – has a strong political function in the sense that happiness (and more broadly a fulfilled life) undercuts the predominance of the so-called medical model of disability. According to this model, disability is seen mainly as a deviance and as a lack resulting from a person’s impairment. The predominance of such a model is attested to by the current widespread use of the problematic notion of *handicap* in a variety of contexts, from education to everyday life. For instance, both the noun *handicap* and the adjective *handicapped* are key terms of the 1992 Italian legislation which regulates the educational and social life of persons with disabilities to this day, at least until a new legislation, more attuned to their rights, comes into force. The definition according to the 104/1992 Law, paragraph 3, clause 1, reads as follows:

> persona handicappata, colui che presenta una minorazione fisica, psichica o sensoriale, stabilizzata o progressiva, che è causa di difficoltà di apprendimento, di relazione o di integrazione lavorativa e tale da determinare un processo di svantaggio sociale o di emarginazione
>
> [handicapped person, someone who has a physical, mental or sensory impairment, either permanent or progressive, which causes difficulties in learning, social relations or work integration and which can lead to social disadvantage or marginalization) (Repubblica Italiana, 1992] (my translation).

Such a definition clearly aligns with the medical model: it identifies the diagnosed impairment as the only cause of difficulties for their development, their socialization, and their inclusion. Legal definitions are informed by the medical model with important social and cultural implications, an aspect I return to in section 4. In contrast, the claim of the possibility of happiness, which is staged throughout the video, challenges the medical conflation of defective bodies with defective lives and of abled bodies with fulfilled lives.

The video’s second claim (“Together we can make it possible”) encourages the audience to contribute actively towards making these people happy since persons with disabilities are often prevented from being so. This is not because of a medical impairment, but because of the social barriers that the medical model and the subsequent social prejudices erect in front of them. Indeed, within the social model of disability, disability is a social construct: barriers are socially constructed, leading to a lack of accessibility for people with disabilities, which in turn reinforces the conflation of defective bodies with defective lives. This perspective has been adopted by international organizations. For instance, the UN Convention on the Rights of Persons with Disabilities (2006) defines disability as follows: “persons with *disabilities* include those who have long-term physical, mental, intellectual or sensory *impairments* which in interaction with various *barriers* may hinder their full and effective participation in society on an equal basis with others” (Art. 1, UN, 2006, p. 4). More specifically, the WHO’s *International Classification of Functioning, Disability and Health* (ICF), for which “disability is complex, dynamic, multidimensional, and contested” (WHO, 2011, p. 3), reminds us that the medical and social models are not dichotomous.

A third model is encouraged as a balanced compromise to replace the medical model and the narrative of disability as a lack or a deviance while taking into account the complexity of the lived experience of disability and of the social perceptions of disability. Referred to as the “bio-psycho-social model”, the third model frames disability as “the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO, 2011, p. 4). In this light, the claim that “together we can make it possible” echoes such a model by reminding us of our joint responsibility towards these people’s happiness: it stages mothers’ love, affection, care and the reciprocal love between them and their children, and concludes with an invitation to everyone to participate actively in making all of this possible. While the video does not suggest or indicate how to act, it promotes awareness of the right of such individuals to be happy, like everyone else, including us viewers. Such an awareness is the starting point, a first step, towards actively participating in the pursuit of a common well-being.

Finally, the third claim (“Everyone has the right to be happy”) frames the right to happiness as a collective right and therefore as a human right that should be advocated and fully exercised. Rather than being conceived as an individual achievement, happiness becomes a social and common goal, one that includes persons with disabilities, and nobody should be left behind. This socially framed notion of happiness is expressed in the first claim (the possibility of happiness) and in the second claim (our joint responsibility in making it possible), visually sustained by the use of small letters. The final claim is written instead in capital letters, as shown in figure 1 below:

DEAR FUTURE MOM | March 21 - World Down Syndrome Day | #DearFutureMom

EVERYONE HAS THE RIGHT TO BE HAPPY.

#DearFutureMom

Figure 1: *Dear Future Mom:* third concluding claim

Placed next to the logo of the 21 World Down Syndrome Day, the right to be happy, commonly perceived as an individual right, becomes a social, local, national, and, at the same time, global, universal right beyond geographical, cultural, and political borders.

3.3 Dear Future Mom as "political translation"

The analysis of *Dear Future Mom* above shows what a "political translation of disability" may look like and may mean. *Dear Future Mom* means rethinking and re-imagining disability to "denaturalize it" (Garland-Thomson, 2018, p. 1557) while revealing the linguistic and cultural nature of our perceptions of disability, as feminist disability studies aim to do. In line with the recent participatory and user-centred media accessibility approach, *Dear Future Mom* makes common citizens – such as persons with disabilities – the protagonists of the film and it allows them to claim their right to be active members of society. And it does so through multi-layered translation that projects disability as a global concern, to mobilize viewers into global action to put an end to discrimination and inequalities. New models of citizenship, such as the dynamic and multi-dimensional notion of Active Citizenship put forward by Halvorsen and a team of European scholars (2017), can play a pivotal role in such a fight. The active participation of people with Down syndrome in the video confirms Philips' (1995) work on the importance of being present to put an end to the "political invisibility" of persons with disabilities (Halvorsen et al., 2017, p. 9). Conceiving of citizenship from a rights-based perspective (see Cohen, 2009; Marshall, 1992) acknowledges that some people are granted full citizens' rights, whereas others are treated as "semi-citizens" (WHO, 2011). A citizenship approach to disability "assigns power" (Parekh, 2014, p. 233) to persons with disabilities since it places individuals at the centre while focusing on their experience of belonging.

Language and translation practices can contribute to making such participation possible. For instance – but not only – by ensuring access to relevant legislation, life-saving information, and funding. Accessibility therefore needs to be conceived of in terms of human rights, particularly language rights, since they can ensure equality among all citizens (Díaz-Cintas et al., 2007; Greco, 2016; Hirvonen & Kinnunen, 2021). "Political translation" is equally central to paving the way towards cross-cultural and social forms of citizenship that challenge the binary and hierarchical categories of first- and second-class individuals. Acts of translation and self-translation can attest to the lived experience of disability or the lived experience of non-disabled persons who interact with persons with a disability. "Political [self-]translation", therefore, can lead us to rethink our understanding of what it is to be human (see Polezzi, 2012; Taviano, 2019).

Disability activists, artists, and performers have come to a new understanding of disabled bodies and lives through what has been defined as "disability culture" (Cheu, 2009, p. 135) by calling into question stereotypes of disabled people as *freaks* and helpless *cripples*. As Cheu (2009) reminds us, scholars have adopted and, at the same time encouraged, this approach to disability based on the distinction between impairment and disability (see Corker & Shakespeare, 2002; Thomas, 2006). While impairment refers to the physical and psychological medical conditions of the body, disability is the result of a cultural understanding of the disability experience, including stigmas and representations of disabled bodies as defective.

This means that impairment is closely related to the body, whereas disability constitutes a social and cultural phenomenon related to identity issues that are projected onto and construct the other's body (Cheu, 2009) – more precisely the textual body in Spurlin's (2017) definition. It is this cultural idea of disability as a medical impairment which needs to be cured that most disability activists and artists strongly resist while they actively perform and translate their identity and experience of disability.

As an activist audiovisual production, *Dear Future Mom* challenges ableist culture and translates disability politically by revealing the limits of social barriers while confirming the universality of parenting experiences and of parents and children's love for one another – whether any of them have disabilities or not – despite undeniable individual differences. For all the above reasons, *Dear Future Mom* is a political act carried out through multiple layers of translation. Multimodal translation (multilingualism, subtitling, body language) makes the audiovisual content accessible across cultural and linguistic borders. It contributes to the overall significance of the video as an act of "political translation" of disability against ableist views of disability to support social equality for persons with disability. This "political translation" is, to use Garland-Thomson's (2005) words, "academic cultural work with a sharp political edge and a vigorous critical punch" (p. 1557).

3.4. Political re-translation of disability: reception of *Dear Future Mom*

Dealing with and advocating the rights of persons with Down syndrome, and of all persons with disabilities, is a "political translation" that may be politically re-translated by viewers in different ways. The controversial reception of *Dear Future Mom* sadly attests to exclusionary cultural and social perceptions about persons with disabilities which impinge on the advancement of the rights of people with disabilities.

In 2016 *Dear Future Mom* was banned by the French Broadcasting Council. The ban that prevented the video from being shown on television was later upheld by the *Conseil d'État* (France's High Court of Administrative Justice). It was issued after complaints by two women who had terminated their pregnancies because of a diagnosis of Down syndrome. The video was claimed "to disturb the conscience of women who had lawfully made different personal life choices" (Lindeman, 2016). This shows that the video's powerful response to those mothers' legitimate doubts and fears was re-translated as reviving the trauma of women. By staging the experience and voices of different persons with disabilities and their families in order to help expectant mothers imagine the possibility of a fulfilled and happy life for their future children, *Dear Future Mom* (as its title indicates) discards and implicitly challenges the decision of terminating a pregnancy because of a diagnosis of Down syndrome. The medical model of disability and its conflation of defective bodies with defective lives "politically re-translates" *Dear Future Mom*. Indeed, the plaintiffs complained that the people with Down syndrome in the video were "too happy", showing their rejection of the social model of disability – a rejection that extends to legal practitioners and institutions, given the success of the complaint.

In 2020 the French Down syndrome research and care organization, Fondation Jérôme Lejeune, represented by the Alliance Defending Freedom (ADF) International, filed a petition to the European Court of Human Rights (ECHR) to overrule the decision. It did so on the grounds that people with disabilities' freedom of expression had been violated and in order to "defend the expression of the happiness of people with Down syndrome without censorship" (quoted in Sielicki, 2022). However, the ECHR ruled against the petition and dismissed the case as "inadmissible" (EU for Trisomy 21, 2022). This led Elyssa Koren, director of legal communications for ADF International to contest the decision on the ground that no government should "silence the peaceful voices of its citizens" and that censoring the very voices of

> those of persons with Down syndrome sends the signal that persons with disabilities are somehow less worthy of being seen and heard in the public square. … The implication here is that the voices of Down syndrome advocates do not merit "general interest," which serves only to contribute to a culture of discrimination (quoted in Sielicki, 2022).

The ECHR ruling testifies to both the national and the transnational and intercultural nature of discrimination against persons with disabilities, such as those with Down syndrome. It becomes clear that the disability culture has deep and widespread legal, in addition to social and cultural, implications affecting their lives, starting from their right to be born and the right of women to abort. Such a right, recognized by law, is ill-informed in a society that frames disability as a life that is not worth living, starting from the medical advice that pregnant women often receive in these cases. According to rather common experiences, also reported by women friends, medical practitioners often strongly encourage, if not persuade, expectant women to abort when they are faced with a diagnosis of disability, such as the Down syndrome, and even in cases of uncertain diagnoses.

This medical narrative affects the law, as is attested to by the French ban. Therefore, the law may be contested on the medical narratives it reproduces and their social and cultural consequences. For instance, in the United Kingdom, in 2021, Heidi Crowter, a British woman with Down syndrome, and Máire Lea-Wilson, the mother of a child with Down syndrome, filed a case against the Department of Health and Social Care over the *Abortion Act 1967* (c. 87). The Act (c. 87) defines a 24-week time limit for abortions unless there is a "substantial risk" of the child being "seriously handicapped" (s. 1). The two plaintiffs argued that allowing pregnancy terminations up to birth if the foetus has Down syndrome is discriminatory, stigmatizes disabled people, and violates the respect for private life, as provided by article 8(1) of the *European Convention on Human Rights* (1950).[i] In their view, this law affects people's decision to become or not to become a parent (Crawter, 2021). The court, however, dismissed the case. As reported in the Summary: "the principal basis on which the appeal is dismissed is that section 1(1)(*d*) of the Act does not interfere with the rights of the living disabled". It was claimed that the legislation was not unlawful since it aimed to strike "a balance between the rights of pregnant women and the interests of the unborn" (Courts and Tribunal Judiciary, 2022, p. 2). As Lord Justice Underhill's conclusions clearly indicate, the two senior judges claimed that the court could not intervene in these controversies and that only the law should drive their decision on this particular case:

> I should emphasise that this Court, like the [High] Court, is only concerned with an issue of law. The question of whether, and if so in what circumstances, it should be lawful to abort a viable

> foetus on the basis that it will or may be born with a serious disability is one of great sensitivity and difficulty. But it is a question which it is for Parliament, and not the Courts, to decide. The only question for us is whether the way that it was decided in 1990 involves a breach of the Convention rights of the Appellants as people born with such a disability. For the reasons given I do not believe that it does (Courts and Tribunal Judiciary, 2022, p. 3).

Interestingly enough, while apparently acknowledging the controversial nature of the issues at stake, the judges questionably justified their choice by separating the law from its social and cultural implications. Paradoxically, it both neglects and reinforces the fact that the law is informed by medical narratives of disability.

Medical narratives of disability, powerfully contested by the video, fight back in an extremely contentious way, since they posit the human rights of children with Down syndrome to be happy and have fulfilled lives with the pro-life versus pro-abortion debate. We are faced here with different translations of what Spurlin (2017) defines as the "original" (p. 173) textual body, since it is precisely the body of these children which is perceived differently, and therefore "politically translated" at legal, social and cultural levels. The political translation of persons with disabilities as "being worth living" – that is to say, being born, raised with love, and leading a happy life, as performed through the production and dissemination of *Dear Future Mom* – becomes socially unacceptable, not only for the women who have decided to terminate their pregnancy, but also for legal experts who continue to interpret the law through the prism of a medical framework about disability as being defective. Within this framework, the distinction between the abortion of non-disabled and disability-diagnosed foetuses rests on the distinction between lives worth living and those which are not. As attested to by the French ban on *Dear Future Mom* and the *Crowter and Lea-Wilson* case in the United Kingdom, such a distinction is not only socially and culturally accepted, but even legally binding. Ableist predominant views of people with disabilities as outcasts continue to loom large in social, cultural, legal, and institutional practices that, instead of safeguarding persons with disabilities, continue to undercut their human rights. Acts of political translation, such as the production and dissemination of *Dear Future Mom*, are therefore central to transforming the social perceptions of disability across languages, cultures and countries, and also to advancing towards active citizenship. As shown above, the video is therefore re-translated across social and legal contexts and much remains to be done to transform the social perceptions that both affect and are affected by the law.

4. Conclusions

Analysing the significance of activist campaigns, such as that carried out by CoorDown with *Dear Future Mom*, is necessary. The interdisciplinary approach combining critical translation studies, feminist disability studies, and media accessibility adopted in this article is one among several necessary steps towards redressing social inequality and the violation of the human rights of minority groups, such as persons with disabilities. *Dear Future Mom* is an act of "political translation" that questions normality paradigms and their relegation of persons with disabilities to defective bodies, together with socially accepted notions of happiness. It represents persons with Down syndrome as full citizens with full lives who participate as protagonists and turn upside down the perception of disability, shaped by ableist views and the fears of non-disabled people (Erevelles, 2011). The video's concluding claims reinforce the lived experience of happiness that the protagonists and their mothers convey throughout the video. At the same time, they remind us of our joint responsibility to achieve individual happiness. The happiness of each person featured in the video becomes a collective right, as in the case of all other human rights; and this right is strongly advocated and should be fully exercised by every one of us, persons with disabilities included.

The ban of *Dear Future Mom* and the legal cases relating to the video and to the abortion law in the United Kingdom show how disability culture has deep and widespread legal, social, and cultural implications that affect the lives of persons with disabilities. Both cases make clear the extent to which medical narratives and their framing of disability as a life that is not worth living have not only legal consequences: they also prevent women from making informed decisions regarding their pregnancies. The double standards of EU countries, as seen in the French and European rulings, attest to a contradiction between the legal recognition of human rights, on the one hand, and legal verdicts, on the other. The ban on the video (the first verdict examined in this article) violates persons with Down syndrome's right to freedom of speech, whereas the second lawsuit (*Crowter and Lea-Wilson* case) violates their right to respect of their private life. Those courts, at both the national and the European level, which are supposed to safeguard human rights, discriminate against persons with disabilities in favour of non-disabled people.

Like CoorDown, Heidi Crowter, who is determined to continue to fight and appeal to the Supreme Court, has carried out acts of "political translation" in contributing to dispelling negative stereotypes and raising awareness of the lives and rights of persons with Down syndrome and their families. The role of individuals and associations, and civil society at large, becomes central to the fight for safeguarding the human rights of all human beings, including those persons with disabilities. *Dear Future Mom* powerfully challenges discrimination and contributes to encouraging a new narrative about disability against a pietistic image. It does so by giving voice to children and young adults with Down syndrome who actively take part in the fight against the social injustice and inequalities that result from the violation of the human rights of persons with disabilities.

Although the reception of *Dear Future Mom* was controversial, it did garner a great deal of support. Despite the ban, *Dear Future Mom* has had and continues to enjoy significant visibility. It has been watched on Youtube nearly 8.5 million times to this day and the site features numerous messages and requests for authorization to use the video. It has been acclaimed internationally and has received six awards from the Cannes International Festival of Creativity and the Art Directors Club of Europe. As reported by Ansa (the Italian news agency) on 15 April 2024 (Ansa, 2024), *Dear Future Mom* might even have contributed to the very recent decision of the Italian Minister for Disabilities to replace the term "handicapped" with "persons with disabilities" in all Italian legislation. It shows that *Dear Future Mom* and its protagonists (children with Down syndrome and their mothers) contribute to politically translating disability as a matter of human diversity rather than inferiority. This is particularly important as more than a billion people worldwide are estimated to live with some form of disability, which corresponds to about 15 per cent of the world's population. Disability is not necessarily somebody else’s problem, given that, as the World Health Organization (WHO) reminds us, each one of us might become disabled in one form or another during our lifetime.

Acts of political translation deserve more scholarly attention, as it is necessary to investigate further and contribute actively to reinterpreting, translating and self-translating disability. Individuals’ and organizations’ activist campaigns, disabled artists’ performances, and other works of art all constitute crucial translational spaces in which persons with disabilities become (self-)translators of their lived experiences of disability and of their interactions with people with and without disabilities. It is by paying tribute to these translational spaces that, as scholars, we can raise awareness of the social and cultural identities of persons with disabilities and actively promote the full citizenship of all individuals.

References

Abortion Act 1967 (c. 87). https://www.legislation.gov.uk/ukpga/1967/87/contents

Anonymous (2021, May 28). Censure d'un clip sur la trisomie 21: «Une atteinte grave à la liberté d'expression des personnes trisomiques». *Le Figaro*. https://www.lefigaro.fr/vox/societe/censure-d-un-clip-sur-la-trisomie-21-une-atteinte-grave-a-la-liberte-d-expression-des-personnes-trisomiques-20210528

Ansa (2024). *Locatelli: 'Via le parole handicappato e portatore di handicap'*. https://www.ansa.it/sito/notizie/politica/2024/04/15/locatelli-via-le-parole-handicappato-e-portatore-di-handicap-_828a94e3-da15-4f09-9ad8-91827e370c5f.html

Bachmann-Medick, D. (2018). Migration as translation. In D. Bachmann-Medick & J. Kugele (Eds.), *Migration, changing concepts, critical approaches* (pp. 273–294). De Gruyter. https://doi.org/10.1515/9783110600483-015

Baker, M. (2006). *Translation and conflict: A narrative account*. Routledge. https://doi.org/10.4324/9780203099919

Baker, M. (2009). Resisting state terror: Communities of activist translators and interpreters. In E. Bielsa & C. W. Hughes (Eds.), *Globalisation, political violence and translation*. Palgrave Macmillan. https://doi.org/10.1057/9780230235410_12

Baker, M. (2013). Translation as an alternative space for political action. *Social Movement Studies: Journal of Social, Cultural and Political Protest*, *12*(1), 23–47. https://doi.org/10.1080/14742837.2012.685624

Boéri, J. (2022). Steering ethics toward social justice: A model for a meta-ethics of interpreting. *Translation and Interpreting Studies, 18*(1), 1–6. https://doi.org/10.1075/tis.20070.boe

Boéri, J. (2023a). Online ethnography of activist networks of interpreters: An "ethnonarrative" methodology for socio-political change. *The Translator*, *29*(2), 210–230. https://doi.org/10.1080/13556509.2023.2190440

Boéri, J. (2023b). Steering ethics towards social justice: A model for a meta-ethics of interpreting. *Translation and Interpreting Studies*, *18* (1), 1–26. https://doi.org/10.1075/tis.20070.boe

Butler, J. (1999). *Gender trouble: Feminism and the subversion of identity*. Routledge. https://doi.org/10.4324/9780203824979

Cheu, J. (2009) Performing disability, problematizing cure. In C. Sandhal & P. Auslander (Eds.), *Bodies in commotion: Disability and performance* (pp. 135–146). University of Michigan Press. https://doi.org/10.3998/mpub.92455

Cohen, E. F. (2009). *Semi-citizenship in democratic politics*. Cambridge University Press. https://doi.org/10.1017/CBO9780511642333

CoorDown (2021, March 13). *Dear Future Mom*. YouTube. https://www.youtube.com/watch?v=Ju-q4OnBtNU

Corker, M., & Shakespeare, T. (Eds.). (2002). *Disability/postmodernity: Embodying disability theory*. Bloomsbury Publishing.

Courts and Tribunal Judiciary (2022, 25 November). Summary. Crowter and Others v Secretary of State for Health and Social Care [2022] EWCA Civ 1559: Lord Justice Underhill, Vice-President of the Civil Division of the Court of Appeal, Lady Justice Thirlwall, Lord Justice Peter Jackson. https://www.judiciary.uk › uploads › 2022/11

Crawter, H. (2021). *Woman with Down's syndrome loses UK abortion law case*. The Guardian. https://www.theguardian.com/world/2021/sep/23/woman-with-downs-syndrome-loses-uk-abortion-law-case

Díaz-Cintas, J., Orero, P., & Remael, A. (2007). Media for all: A global challenge. In J. Díaz-Cintas, P. Orero, & A. Remael (Eds.), *Media for all: Subtitling for the deaf, audio description, and sign language* (pp. 11–20). Brill. https://doi.org/10.1163/9789401209564

Di Giovanni, E. (2022). Inclusive theatre-making: participation, empowerment and well-being. *InTRAlinea: Online Translation Journal, 24*. https://www.intralinea.org/specials/article/2609

Di Maio, A. (2021). The black mediterranean. *Transition*, *132*, 34–53. https://doi.org/10.2979/transition.132.1.03

Doerr, N. (2018). *Political translation: How social movement democracies survive*. Cambridge University Press. https://doi.org/10.1017/9781108355087

Erevelles, N. (2011). *Disability and difference in global contexts: Enabling a transformative body politic*. Palgrave Macmillan. https://doi.org/10.1057/9781137001184

EU for Trisomy 21. (2022, September 15). *EU for Trisomy 21 reacts to ECHR verdict on the "Dear Future Mom" video*. https://eufortrisomy21.eu/eu-for-trisomy-21-reacts-to-echr-verdict-on-the-dear-future-mom-video/

European Centre for Law and Justice. (2017). United Nations Committee on the Rights of Persons with Disabilities. Written submission on the Draft General Comment No. 6 on the right of persons with disabilities to equality and non-discrimination (article 5). https://www.ohchr.org/Documents/HRBodies/CRPD/GC/Equality/ECLJ_EN.docx

European Court of Human Rights. (1950). *European Convention on Human Rights*. https://www.echr.coe.int/documents/d/echr/convention_eng

Federici, F. M. (2020). Emergenza migranti: From metaphor to policy. In C. Declercq & F. M. Federici (Eds.), *Translation, interpreting and languages in local crises* (pp. 233–258). Bloomsbury. https://doi.org/10.5040/9781350097087.ch-012

Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal, 14*(3), 1–32. https://doi.org/10.2979/NWS.2002.14.3.1

Garland-Thomson, R. (2005). Feminist disability studies. *Signs*, *30*(2), 1557–1587. https://doi.org/10.1086/423352

Gill, R. M., & Guzmán, C.M. (2014). Teaching translation for social awareness in Toronto. *The Interpreter and Translator Trainer*, *5*(1), 93–108. https://www.tandfonline.com/doi/abs/10.1080/13556509.2011.10798813

Greco, G. M. (2016). On accessibility as a human right, with an application to media accessibility. In A. Matamala & P. Orero (Eds.), *Researching audio description* (pp. 20–32). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-56917-2_2

Greco, G. M., & Romero-Fresco, P. (2023). Universalist, user-centred and proactive approaches in media accessibility: The way forward. *The Journal of Specialised Translation*, *39*, 3–10. https://jostrans.org/issue39/art_greco.pdf

Hall, K. Q. (2011) (Ed.). *Feminist disability studies*. Indiana University Press.

Halvorsen, R., Hvindn, B., Bickenbach, J., Ferri, D., & Guillén Rodriguez, A. M. (Eds.). (2017). *The changing disability policy system* (Vol. 1). Routledge. https://doi.org/10.4324/9781315623931

Hirvonen, M., & Kinnunen, T. (2021). Accessibility and linguistic rights. In K. Koskinen & N. K. Pokorn (Eds.), *The Routledge handbook of translation and ethics* (pp. 470–483). Routledge. https://doi.org/10.4324/9781003127970-35

Inghilleri, M. (2017). *Translation and migration*. Routledge. https://doi.org/10.4324/9781315399829

Inghilleri, M., & Polezzi, L. (2020). A conversation about translation and migration. *Cultus*, *13*, 24–43. https://www.cultusjournal.com/files/Archives/Inghilleri_Polezzi.pdf

Lindeman, R. (2016). *Censored: video "Dear Future Mom"*. Huffpost. https://www.huffpost.com/entry/c-e-n-s-o-r-e-d-video-dear-future-mom_b_582f8e6fe4b0d28e55214ef6

Magris, M. (2018). The translator as social agent: The case of the UN Convention on the Rights of Persons with Disabilities. *Rivista Internazionale di Tecnica della Traduzione*, *20*, 101–115. https://doi.org/10.13137/2421-6763/23192

Marshall, T. (1992). Citizenship and social class. In T. Marshall & T. Bottomore (Eds.), *Citizenship and social class* (pp. 3–51). Pluto Press. https://www.plutobooks.com/9781783713585/citizenship-and-social-class/

Matamala, A., & Orero, P. (2018). Standardising accessibility: Transferring knowledge to society. *Journal of Audiovisual Translation*, *1*(1), 139–154. https://doi.org/10.47476/jat.v1i1.49

Meng, J., & Laviosa, S. (Eds.). (2020). *The Oxford handbook of translation and social practices*. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190067205.013.2

Parekh, G. (2014). *Social citizenship and disability: Identity, belonging, and the structural organization of education* [Unpublished doctoral dissertation]. York University.

Pérez-González, L. (2010). 'Ad-hocracies' of translation activism in the blogosphere: A genealogical case study. In M. Baker, M. Olohan, & M. Calzada Pérez (Eds.), *Text and context essays on translation and interpreting in honour of Ian Mason* (pp. 259–287). St Jerome Publishing. https://doi.org/10.4324/9781315759739

Pérez-González, L. (2016). The politics of affect in activist amateur subtitling: A biopolitical perspective. In M. Baker & B. Blaagaard (Eds.), *Citizen media and public spaces: Diverse expressions of citizenship and dissent* (pp. 118–135). Routledge. https://doi.org/10.4324/9781315726632

Piróth, A., & Baker, M. (2020). Volunteerism in translation: Translators without borders and the platform economy. In E. Bielsa & D. Kapsaskis (Eds.), *The Routledge handbook of translation and globalization* (pp. 406–424). Routledge. https://doi.org/10.4324/9781003121848-33

Polezzi, L. (2012). Translation and migration. *Translation Studies*, *5*(3), 345–356. https://doi.org/10.1080/14781700.2012.701943

Repubblica Italiana. (1992). Legge 5 febbraio 1992, n.104. *Gazzetta Ufficiale della Repubblica Italiana*. https://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg

Romero-Fresco, P. (2019). *Accessible filmmaking: Integrating translation and accessibility into the filmmaking process*. Routledge. https://doi.org/10.4324/9780429053771

Sielicki, B. (2022, September 12). *European Court rules against free speech in Down syndrome video ban*. Liveaction. https://www.liveaction.org/news/european-court-down-syndrome-ban/

Smith, S. L., Choueiti, M., & Pieper, K. (2017). *Inequality in 900 Popular Films: Examining portrayals of gender, race/ethnicity, LGBT, and disability from 2007–2016. Media, Diversity and Social Change Initiative*. Annenberg Foundation/USC Annenberg. https://annenberg.usc.edu/sites/default/files/Dr_Stacy_L_Smith-Inequality_in_900_Popular_Films.pdf

Spiśiaková, E. (2021). Disability in translation. In Ş. Susam-Saraeva & E. Spiśiaková, *The Routledge handbook of translation and health* (pp. 300–313). Routledge. https://doi.org/10.4324/9781003167983-23

Spurlin, W. (2017). Queering translation: Rethinking gender and sexual politics in the space between languages and cultures. In B. J. Epstein & R. Gillett (Eds.), *Queer in translation* (pp. 172–183). Routledge.

Taronna, A. (2015). La mediazione linguistica come pratica di negoziazione, resistenza, attivismo e ospitalità sulle sponde del Mediterraneo. *Lingue e Linguaggi*, *16*, 159–175.

Taviano, S. (2019). The counternarratives of migrants and cultural Mediators. In F. M. Federici & C. Declerq (Eds.), *Intercultural crisis communication, translation, interpreting and languages in local crises* (pp. 21–38). Bloomsbury Academic. https://doi.org/10.5040/9781350097087.ch-002

Taviano, S. (2020). The migrant invasion: Love speech against hate speech and the violation of language rights. In G. Balirano & B. Hughes (Eds.), *Homing in on HATE: Critical discourse studies of hate speech, discrimination and inequality in the digital age* (pp. 247–263). Paolo Loffredo.

Taviano, S. (2023). Translating migration: art installations against dehumanizing labelling practices. *Translating otherness: Challenges, theories, and practices*. *Languages*, *8*(3), 1–14. https://doi.org/10.3390/languages8030221

Taviano, S. (2024). Translating disability towards social justice: Turning representations of persons with disabilities upside DOWN. *Linguistica Antverpiensia, New Series: Themes in Translation Studies*, 23, 210–228.

Taviano, S. (2025). Translation, migration and hospitality: Migrant artists as agents of translation. *The Routledge handbook of translation and migration* (pp. 205–220). Routledge. https://doi.org/10.4324/9781003287797-17

Thomas, C. (2006). Disability and gender: Reflections on theory and research**.** *Scandinavian Journal of Disability*, *8*(2–3), 177–185. https://doi.org/10.1080/15017410600731368

World Health Organization (WHO). (2011). *World report on disability*. https://www.refworld.org/docid/50854a322.html

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[i] "1. Everyone has the right to respect for his private and family life, his home and his correspondence. 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."