dis/ability

by Stefania Taviano

Abstract:

*Partendo dalla **definizione di disabilità** delle Nazioni Unite, basata sul modello sociale in quanto definita come **socialmente costruita** e legata alle **barriere sociali**, metto in discussione la visione predominante della disabilità, basata invece sul **modello medico** che vede la disabilità come un **limite**, il risultato della menomazione di una persona. Termini **discriminatori,** come 'handicap' e 'disabile', continuano a essere applicati in molti contesti, tra cui l'istruzione e le leggi. Come **studiosa** di **traduzione** e come **madre** di un **ragazzo** di 11 anni con la **sindrome di Down** sono impegnata nella **promozione** della **giustizia sociale,** e contesto queste rappresentazioni delle persone con disabilità che, unite a discorsi discriminatori, possono giocare un ruolo centrale nel **permettere** o **impedire** a queste persone di godere dei **diritti umani**. La **lotta** contro le **disuguaglianze sociali**, portata avanti dalle organizzazioni nazionali e internazionali di persone con disabilità, è anche messa in scena e rappresentata da **artisti disabili,** che esprimono con forza la **pluralità** delle **persone** con **disabilità** e attraverso la loro arte diventano agenti della loro identità, rivendicando chi sono e interpretando la disabilità come **diversità umana**, piuttosto che come **inferiorità**.*

In this entry, I address **predominant views** of **disability**, challenging **discriminatory representations** and **discourses** that see **disability** as the result of a **person's impairment**, and which can play a central role in allowing or preventing these people from enjoying **human rights**. I will then show how though **creativity artists with disabilities** become agents of their **identity** by claiming who they are and by interpreting **disability** as **human diversity**, rather than **inferiority**.

Etymology:

Dis-ability is formed by the prefix **dis**-, meaning incapacity, and the word **ability**, meaning and involving power, strength. The term **disability** is thus an **oxymoron** in itself since the **prefix denies** the **ability**, a capacity inherent to the word itself, like all words formed by a negative prefix, such as dyslexic, dyscalculic, dysfunctional, do. The **negation** expressed by the prefix **dis**- is undeniable related to **normative** and **ableist standards**, that is to say what society at large, together with law, health and education systems, consider and value as ability, thus 'normal' and acceptable.

Problematization:

The **United Nations** defines **disability** as follows in Article 1 of the *Convention on the Rights of Persons with Disabilities* (2006): "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" (UN, 2006, p. 4).

Such a **definition** is informed by the so-called **social model of disability** which frames disability as **socially constructed** and **connected to social barriers** preventing persons with disabilities from **having access** to a **series of services**, **social contexts** as well as **human rights**. Persons with disabilities, however, have been, and more often than not, continue to this day to be defined according to the **medical model** which **sees disability as a limit**, as the result of a person's impairment and discriminatory terms, such as '**handicap**', continue to be applied in different contexts, including law and education systems, in several countries.

The **definition** of persons with disabilities, as in the case of other social groups and categories, such as **gender** and **race**, in fact refers to **people** with a **wide variety** of **physical** and **cognitive differences**, who are nevertheless **grouped** in an **apparently homogenous social class**, and are subject to **oppression** while being socially and politically **invisible** (Garland-Thomson, 2005). The ways people belonging to minority groups, including migrants and asylum seekers, are categorised have a serious impact on their lives (Federici 2020, Taviano 2020) to the point that **labelling practices** contribute to the **violation of their rights**.

The **WHO**'s *International Classification of Functioning, Disability and Health* (ICF) aims to go beyond such views and further specifies that "**disability** is **complex**, **dynamic**, **multidimensional**, and **contested**" (WHO, 2011, p. 3) while encouraging a **third model**, a compromise beyond the dichotomy between the **medical model** and the **social model**. This is the **bio-psycho-social model**, which aims to take into account the **multifaceted nature of disability** and is framed as an "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).

Despite such changes in international organizations' approach to disability, both the noun '**handicap**' and the adjective '**handicapped**' are **key terms** of the **1992 Italian legislation** which has regulated the educational and social life of persons with disabilities **before** a recent decree law which has come into force in **June 2024**. The definition, according to the previous 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, psychic or sensorial impairment, either stable or progressive, which causes learning, relational difficulties or difficulties in terms of job integration and which can lead to social disadvantage or discrimination) (Repubblica Italiana, 1992).

Such a definition, which clearly identifies the **person's impairment** as the only cause of **social discrimination** follows the medical model and **continues to be used** in official **signs**, **documents** and **educational contexts** despite the Italian Minister for Disabilities' official statement on 15 April 2024 that the term '**handicapped**' will be replaced with '**persons with disabilities**' in all Italian legislation. Some schools, for instance, where the groups of special needs teachers are still defined as GLH or H (handicap workgroups) rather than GLO [*Gruppo di Lavoro Operativo per l'inclusione* - Operational Group for inclusion] as provided by the Law 66/2017, which has replaced GLHs with GLOs.

Similarly, the definition '**seriously handicapped**' was used by **British judges** referring to **British abortion legislation** in 2021 when Heidi Crowter, a British woman with Down syndrome, and Máire Lea-Wilson, mother of a child with Down syndrome, went to court over the UK's abortion law, and lost their case in the high court. The two women filed a case against the Abortion Act 1967, particularly the 24-week time limit for abortions except in the case of a "substantial risk" of the child being "seriously handicapped". These women rightly claimed that such a **law violates** the **respect** for **private life,** as provided by article 8(1) of the European convention on human rights (ECHR), and that allowing pregnancy terminations up to birth if the foetus has Down syndrome is a clear instance of discrimination against persons with disabilities recognized by law.

Subversion:

In recent years **national** and **international associations** and **organizations** of **persons with disabilities**, as well as individuals, **artists** in particular, have been questioning and **fighting against social labels** and **patterns of exclusion**, stigmatizing them as defective on the basis of ability norms through activist campaigns. Thanks to these campaigns **persons with disabilities** become **agents of their identity** by claiming who they are and by **interpreting disability** as **human diversity**, rather than **inferiority**. Through their own experiences they show us that **reinterpreting disability means questioning ableist rhetoric** and standards of 'normality' against which these people are judged as unworthy citizens (Erevelles, 2011) while encouraging positive identity politics.

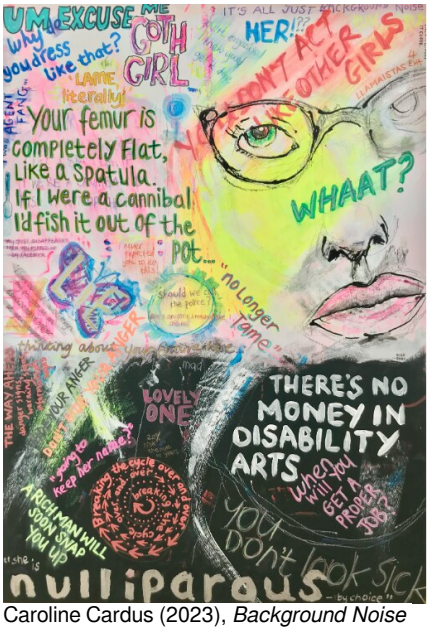
This is what disabled artists of the **IN/Visible Disabled Women's National Arts Collective**, aimed to do, for instance, with the exhibition ***All The Women I Could Have Been****,* UK*,* August 2023.
https://www.littlecog.co.uk/invisible-exhibition-2023.html

These artists explore narratives about **disabled women** and **their rights**, the close connection between **justice** and **arts movements** while celebrating 'who we are'.

Here below you can see two of the works that were presented at the afore mentioned exhbition. They are respectively

Caroline Cardus's, ***Background noise***, and Honor Flaherty's, ***Words of Mass Destruction and Other Stubborn Stains***.

Caroline Cardus's work focusses on **creative activism**. Starting from her own **experiences as a disabled woman**, Cardus's text based, **subversive** and **graphic style work** delivers **frank**, **darkly humorous** and **powerful messages** about **disability discrimination** and **diversity**. Commenting her work ***Background Noise***, she says: "My piece contains **fragments** that **stayed** with **me** over the **years** that were **annoying**, **shocking**, or **funny.** Some I sanded off or painted over, some are louder or quieter, but **all contributed to questions of who I might be**. The **body** I inherited, along with **time** and **empowerment**, gradually brought me the **realisation** that I couldn't have been **anyone other** than the **person** I am **now**".
Further info on the artist and her work at:
www.carolinecardusartist.com



Caroline Cardus (2023), *Background Noise*
(70 x 50 cm; mixed media on board)
Courtesy of the Artist



Honor Flaherty, (2023). *Words of Mass Destruction and Other Stubborn Stains.*
(Mixed materials)
Courtesy of the Artist



A **stage** and **screen writer** with a penchant for **comedy** and **camp musicals**, the artist describes the work ***Words of Mass Destruction and Other Stubborn Stains*** as: "It is a **washing line textile art pieces** depicting **saying**/**quotes** that **were once said to me**, over a life time, to **deter** or **stamp on my dreams**. It's essentially about **how words can hurt or heal**".

Disabled performance artists similarly **stage disability** to **promote social justice** and persons with disabilities' human rights, in the same way as organizations of persons with disabilities do for the safeguard of disability rights. **Maysoon Zayid**, an activist comedian, co-founder of the **New York Arab-American Comedy Festival**, has been

advocating social justice for persons with disabilities throughout her career. She started with **her performance** at the 2013 *Ted Women Conference* in San Francisco, *I got 99 problems, palsy is just one* where she **verbally** and **physically delivers her disability** right from the title and the very beginning of the performance, which is known worldwide. She is also the founder of **Maysoon's Kids**, a **scholarship** and **wellness program** for **disabled and wounded refugee children** in the **West Bank**. Activism is at the centre of her performances, together with disabled performers, who aim to *de-naturalise* disability (Kuppers 2001: 26).

When **introducing herself** during her **performance** she does so by explaining the audience that rather being born this way, she got **cerebral palsy because the gynecologist** "cut my mom six different times in six different directions, suffocating poor little me in the process. As a result, I have cerebral palsy, which means I shake all the time. […] I'm like Shakira, Shakira meets Muhammad Ali.[1] **Her body**, **rather than being hidden**, becomes the **focus** of her i**ronic introduction** of **herself** as a hybrid resulting from the encounter of the singer Shakira and the boxer Muhammad Ali. She makes **her audience laugh** while **calling into question** a whole series of **prejudices about disability**: she argues that hers is not genetic nor infectious, and she ironically denies the idea that a defective body might be the result of evil forces and curses.

The **performance** of **disability** by **disabled artists**, such as Zayid, who reveal the **social nature of disability** culture and ableist scripts through self-translation of their own bodies and identities **is vital** to **fight** against the **pervasiveness** of **discriminatory social labelling**. Those **performances** acquire a **political value** as key elements of the global movement for **disabled rights** and at the same time oblige us to address on our responsibility as able-bodied spectators and citizens.

Disability as a **form** of **art**, and **different forms** of **art by persons with disabilities**, remind us that the **centrality** of the **disabled body**, with its **unique characteristics** and human imperfections, is closely related and **cannot be separated** from a **person's value** and **identity**, and that **bodies** contribute to who **we are** as **human beings** actively making **choices within** a **social** and **political context**. Furthermore, **disability arts** in many forms create **spaces** and **environments** where persons with disabilities can **share** and **promote** an **awareness** of **disabled identities**.

Turning disability upside Down

Resistant arts practices, such as the ones mentioned here, together with **individual** and **collective social practices**, and a **new language about disability**, can thus contribute to **reversing dehumanizing practices** by placing **people's identities at the centre** (Taviano 2023, Taviano 2025). This is what activists, artists, particularly **my 11-year-old son with Down syndrome** have taught me, a lesson which I would like to share and conclude by encouraging all of us to do the same: that is ***turning upside Down* our understanding** of **dis-ability(ies)**, thus of **human diversity.** As **Sammy Basso**, the longest living survivor of a rare rapid-aging disease, progeria, who has recently died at 28, has written in a letter for his funeral: "**we are all disabled because we are all different**".

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[1] This and all citations from the transcript of Zayid's *Ted Talk, I got 99 problems… palsy is just one* are available at https://www.ted.com/talks/maysoon_zayid_i_got_99_problems_palsy_is_just_one/transcript.

Discussion:

- Do we pay attention to the way we define persons with disabilities and how they are defined by people around us?
- How do we interact with them? Do we exclusively offer to help them as people in need?
- How can each of us contribute to challenge discriminatory representations of persons with disabilities in the workplace and everyday life?

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