

The shame–blame complex of parents with cognitively disabled children in Italy

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Abstract

This article aims to advance knowledge related to the concept of the ‘shame–blame complex’ by analysing the accounts and experiences of parents with cognitively disabled children. It draws on 29 interviews with parents of children with Down syndrome and shadowing sessions with one family, carried out in Italy. Results show how the feeling of shame as a consequence of being associated with a disabled child is turned into blame for bad parenting. The sources of this blaming process are twofold: firstly, neoliberalism has disseminated an intensive parenting model based on the imperative of individual responsibility and risk avoidance. Secondly, ableism acts as a network of processes and beliefs that produce a particular kind of self and body as the perfect and complete human being. Participants have been held responsible for their children’s condition because they avoided prenatal screening or continued a pregnancy after receiving a positive result. Consequently, parents’ moral culpability for their children’s diversity and their social marginalisation were enhanced. Although the interviewees resist the shame of being associated with a cognitively disabled child and the blame for bad parenting, they seem unable to escape from the grips of the shame–blame complex. The latter has structural and cultural underpinnings. In an age of

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‘neoliberal-ableism’, this complex is indeed a powerful weapon to erode the rights of families with cognitively disabled members.

KEYWORDS

blame, cognitive disabilities, intensive parenting, shame, stigma

INTRODUCTION

Sociology has traditionally distinguished between stigma, related to a form of ontological deficit (Scambler, 2004, 2018) for which the bearer is not held responsible, and deviance, a form of behaviour charged with moral culpability (Scambler, Paoli, 2008). Stigma therefore refers to the possession of an ‘ascribed’ condition and the logic of shame, whereas deviance refers to an ‘achieved’ or moral condition and the logic of blame (ibidem). However, drawing on 29 interviews with parents of children with Down syndrome and shadowing sessions with one family, this article argues that a combination of both phenomena, called the ‘shame–blame complex’, can create the cultural marginalisation of these families. The article thus contributes to the body of literature on the courtesy stigma of families with a disabled member, by showing its different macrostructural *and* subjective dimensions. In line with Gareth Thomas’ work (2021) it shows not only the effects of individualised stigma realised in microlevel interactions (shame), but also the impact of structural stigma emerging from power dynamics (blame). In this context, the article provides a further contribution by both ‘dissecting the banal, taken-for-granted moments of everyday life’ (ibidem: 463) and by analysing the overlaps between the different analytical concepts of shame and blame.

DISABILITY AND (COURTESY) STIGMA

Drawing on Goffman’s (1963) seminal theoretical work in this area, studies on the courtesy stigma of families with a disabled member (see, for instance, Farrugia, 2009; Francis, 2012; Gray, 2002; Green, 2003; Manago et al., 2017; Song et al., 2018) explored the nature and management of parents’ ‘spoiled’ social identities. The latter results from affiliation with the stigmatised child. Stigma, which can be defined as a deeply discrediting attribute producing a negative public reaction, affects the individuals’ sense of self and disrupts their full participation in working and social life (Link et al., 1989). In a society ‘in which beauty, health and independence are highly valued, individuals with disabilities can be conceived as the bearers of negatively valued traits’ (Green, 2003, p. 1361). These traits can thus overshadow other characteristics, becoming an indication of general incapacity. Goffman (1963) argued that the stigma label tends to spread to people with whom the bearer of negative traits is associated. The members of this category are forced to share some of the discredit brought upon the disabled person. They may experience stigmatisation ‘because of the affiliation with the stigmatised individual, rather than any characteristic of their own’ (Goffman, 1963, p. 30). While most studies have focused on the experiences of persons who possess a discrediting attribute, the concept of courtesy stigma has received little scholarly attention (e.g. Birenbaum, 1992; Dako-Gyeke, 2018; MacRae, 1999).

Disability studies scholars have criticised the micro-social focus of interactionist studies. This focus presumed that there is a value consensus between ‘normal’ and stigmatised people about

who is 'a normal human being' and who is not (Barnes & Mercer, 2010). Interactionist studies, thus, ignored the social processes that construct diversity. Proponents of the social model of disability have considered stigma an inadequate heuristic because of its apolitical nature.

However, later developments in medical sociology (Link & Phelan, 2001; Scambler, 2009) went beyond the descriptive microanalysis made possible by the previous notion. They drew on both disability studies and sociology to establish a new approach to stigma with more analytical value. In this work, stigma is defined as the critical co-occurrence of its components: labelling, stereotyping, separation, status loss and discrimination, since power must be exercised in order to exist (Link & Phelan, 2001). Scholars have expanded the stigma construct in such a way that stigmatisation is conceptualised as a sociocultural process, which operates to reproduce structural power relationships and exclude stigmatised individuals from the social world (Scambler, 2018, 2020).

DISABILITY STIGMA IN THE AGE OF NEOLIBERAL-ABLEISM

Graham Scambler described the process by which stigma (i.e., norms marking an ontological deficit, non-conformance or shame) has been redefined as deviance (i.e., norms marking a moral deficit, non-compliance or blame), mainly for political purposes via 'the weaponising of stigma' (2018). Scambler (2018), drawing on his classical distinction between enacted stigma (actual discrimination) and felt stigma (an internalised sense of shame) has shown how both overlap with felt and enacted forms of deviance. Financial capitalism and the class command dynamic, which fuels a neoliberal ideology, blame vulnerable people like disabled individuals for failing to stick to the imperatives of capital accumulation. Stigmatised people are portrayed as deviants who somehow deserve their misery. Stigma, then, has a political economic dimension, in which disabled people are devalued and cast in an age of 'neoliberal-ableism' (Goodley, 2014). Their rights are undermined and they encounter hostility and indifference (Charmaz, 2020; Thomas, 2021). In this article, I contend that the political economic dimension of stigma for cognitively disabled people is related to both ableism and neoliberalism in specific ways. On the one side, ableism is a network of beliefs, processes and practices producing a particular kind of self and body as the perfect and 'normal', complete human being (Campbell, 2012). It frames disabled people as defective owing to their physical, sensory, and cognitive impairments, thus strengthening a deficit narrative. On the other side, neoliberalism is an ideology that describes good citizens as entrepreneurial subjects guided by specific rules that emphasise ambition, calculation and personal responsibility (Rose, 1992). The processes of ableism and neoliberalism currently feed off each other to foster individual responsibility and accountability and reduce state support. Thus, they exclude disabled people and their families who fail to meet the preconditions to enter the capitalist marketplace (Goodley, 2014).

A small number of studies have shown that parents of disabled children can express agency and negotiation of discourses about disability and personhood by appropriating medical knowledge (Farrugia, 2009; Scavarda & Cascio, 2022) as well as challenging conceptions of normalcy (Manago et al., 2017; Scavarda, 2020a, 2020b; Thomas, 2021) and resisting the pessimistic view of a deficit narrative. However, parents of disabled children are exposed to the intertwining forces of ableism and neoliberalism through the dominance of intensive mothering and, more generally, intensive parenting discourse (Hoffman, 2010; Shirani et al., 2012).

DISABILITY AND INTENSIVE PARENTING

In recent years, the phenomenon of intensive or hyper-mothering/parenting has been defined as a highly demanding, child-centred approach to child-rearing, which is both a time-consuming

and emotionally intensive enterprise (Hoffman, 2010). The term 'intensive mothering' and the collated concept of the 'good mother' were originally adopted by Hays (1996) to describe a model of parenting according to which parents are 'expected to acquire detailed knowledge of what the experts consider proper child development and then spend a good deal of time and money attempting to foster it' (Hays, 1996, p. 8).

The implicit pressures of parental responsibility in intensive parenting can be considered part of the broader neoliberal project (Henwood et al., 2010) in that they emphasise individual responsibility and self-management alongside a focus on managing risk (Shirani et al., 2012). Parents are increasingly held responsible for risk management and life planning, and 'bad parenting' is deemed to lead to numerous social problems (Hoffman, 2010). Therefore, parents who are single, poor, non-white, immigrant, homeless, lesbian or whose children are 'disabled' or 'deviant' are judged to be bad parents (Francis, 2012). Parents of disabled children, and particularly mothers, are still exposed to stigma and inequalities (Thomas, 2021). In this context, Sousa's (2011) analysis of the 'warrior hero' identity of mothers of cognitively disabled children is particularly relevant. The 'warrior hero' figure is a subcategory of the 'good mother', specifically a mother who battles to obtain resources and cures for her children. While mothers were once considered responsible for their children's disabilities, in line with the psychoanalytical theory of the 'refrigerator mother', this dynamic has shifted such that mothers are now held responsible for curing them or finding solutions to alleviate the effects of disability on their children's health and everyday life (ibidem). Linda Blum (2007) also claimed that mothers of children with invisible disabilities are blamed if they do not make substantial efforts to eliminate their children's problems. Although Sousa and Blum reported a cultural shift in the perception of mothers' role in their children's disability, from causing it to curing it, some scholars in the field of mental illness highlight that genetic paradigms have impacted on the idea of parental responsibility. The blame for incompetent mothering/parenting nowadays has been turned into the blame for procreating (Phelan et al., 2002). This blame is related to the neoliberal prescription to manage and avoid risks (Henwood et al., 2010), and particularly genetic risks, by making responsible reproductive choices (Finkler, 2001). Good neoliberal citizens are expected to self-regulate and minimise any potentially risky behaviours that may imply costs for the State or themselves (Rose, 1990). The current belief that human beings can control the risk of inheriting a genetic disease is widespread and affects the orientations of future parents (Finkler, 2003).

This article combines these two research streams, analysing how and how much parents of children with Down syndrome are subjected to both blame and shame. More specifically, it examines how the shame of having a child with a congenital cognitive condition is turned into the blame for bad parenting. Moreover, it discusses the strategies of resistance to this joint process that parents actively play out in their everyday lives.

Resistance to regimes of power in the field of health and illness is a wide topic (Armstrong, Murphy, 2012). This body of literature applies Foucauldian concepts to highlight how public health imperatives prompt individuals to adopt health promotion practices and healthy lifestyles to be considered good citizens (see for instance Lupton, 1995). As an expression of the neoliberal good citizen model in the health domain, these imperatives are subtle and nuanced ways in which power operates in society through specific technologies of domination (Foucault, 1984). According to Foucault, power always implies forms of resistance because there must be a certain degree of freedom on both the side of those exercising it and the side of those on whom it is exercised (ibidem). Later work suggests that resistance may take complex and flexible forms beyond the refusal of dominant discourses (see Weedon, 1987). Feminist scholarship explored how women negotiate and develop different meanings and behaviours on the margins of power (Davis &

Fisher, 1993). Thoughts and actions in everyday life, although not necessarily challenging power structures, may transform powerful discourses and modify power relations (Armstrong, Murphy, 2012). Until recently, these nuanced forms of resistance have been empirically underdeveloped (*ibidem*). However, drawing on these theoretical developments, some scholars argued for the analysis of stigma and resistance as an exploration of subjectivity and the negotiation of power relations (Farrugia, 2009). In this article, I rely on this concept of resistance, to show how parents of children with Down syndrome reject shame and blame in diverse and diffuse ways.

THE RESEARCH: AIMS AND METHODS

The results discussed in this article are part of a larger qualitative study that examined the origins of the shame–blame complex among families with children/young people with autism and Down syndrome. The broader study involved in-depth interviews with parents, children and young people/adults with Autism and Down syndrome and health-care professionals; shadowing sessions with two families; and participant observation in three services targeting people with Autism and Down syndrome. For this article, I focus on the results of only the interviews with parents of children with Down syndrome and the shadowing sessions with one family with a child with Down syndrome.

Analysis addressed the following research questions: How do parents of people with Down syndrome experience and represent blame and shame? Do they resist them? If so, which forms of resistance do they play out? Are their strategies of resistance successful in challenging negative assumptions about disability?

This paper focuses on parents' experiences because they often find themselves in a liminal position between 'proper' parenthood and 'proper' disability activism (Ryan, Runswick Cole, 2019). The interplay between these intersecting identities is currently underdeveloped. Moreover, non-disabled mothers of disabled children have sometimes been conceived as agents of oppression (Thomas, 2017) even if they have proved to be able to frame their children's diversity as a challenge to societal norms (Piepmeier, 2021).

The research was conducted in Piedmont, a region in the north-west of Italy with a longstanding tradition of health-care services devoted to people with cognitive disabilities and a strong presence of parents' advocacy associations. This specific situation assisted with recruitment. In Italy, and particularly in the northern regions, both health services and advocacy associations have historically been inspired by a medical approach to disability that is neurobiologically informed (Scavarda & Cascio, 2022) and by a Catholic view of disability (Medeghini et al., 2013). The latter generally conceives disability as a sign of divine incarnation and a form of suffering people are called to endure (*ibidem*). Italy provides an interesting context for the study of disability stigma thanks to this dualistic sociocultural influence.

Although the original research is comparative and confronts two very different subpopulations, namely parents of children with Down syndrome and with Autism with lower levels of support needs, in this article I will focus only on parents of children with Down syndrome. Down syndrome is a chromosomal condition that can be discovered at birth, or even before, through prenatal screening tests. For this reason, it is an interesting case to study the interplay of blame and shame and the effects of the genetic paradigms on parental responsibility. According to the most recent national survey (Fondazione Censis and Serono, 2012), while Down syndrome is well known in Italy, misconceptions are widespread. The survey reports that 81.2% of the respondents knew that Down syndrome is a genetic condition and 77.6% agreed that a mother's advanced age is a risk factor for having a child with Down syndrome. Half of the interviewees responded that

TABLE 1 Socio-demographic characteristics of the sample.

Type of condition	
Down syndrome	29
Age	
3–10	9
13–19	10
21–27	10
Gender	
Male	18
Female	11
Socioeconomic status (SES)	
Middle-low	16
Middle-high	13
Types of recruitment sites	
Paediatric clinical units	14
Parents' associations	15
Total	29

Down syndrome is not always associated with learning difficulties, thus paradoxically fostering the stigma of the cognitive difficulties of people with Down syndrome because they could 'have been avoided' (ibidem: 16). However, individuals with Down syndrome are monitored for a range of specific health issues. The National Institute of Health issued some guidelines for the integrated care of people with Down syndrome (url.it/3tm11), which prescribed a detailed follow up protocol to monitor the onset of specific problems (visual and motor impairments, heart defects). The provision of preventive measures, as well as health and therapeutical activities, have improved the quality of life of people with Down syndrome in Italy over the last 20 years (ibidem). Nonetheless, because of this detailed schedule of doctor visits and check-ups, the presence of a person with Down syndrome within a family is supposed to imply a care-giving burden for parents (ibidem).

Families were recruited from both paediatric clinical units and local parents' associations, using theoretical sampling (Silverman, 2015) aimed at ensuring the heterogeneity of the sample related to theoretically relevant properties. The sample is made up of 29 families with either a middle-low or a middle-high socioeconomic status, whose children belong to different age groups and are predominantly male (see Table 1). This intentional gender imbalance allowed for more direct comparison with families of autistic children in the broader study, due to the 3:1 male-to-female ratio of autism diagnoses (Loomes et al., 2017).

Data collection methods included in-depth interviews with parent couples and shadowing. Interviews lasted about one and a half hours and were recorded and fully transcribed. Shadowing (Czarniawska, 2007) is a radical form of participant observation, in which the researcher observes a person or a group of people for full eight-hour days. For one week, I followed one family—with a 15-year-old child with Down syndrome (Matteo) during its daily activities and encounters with social and health-care professionals. Shadowing allows the researcher to capture the full range of details of someone's daily life and is grounded in actual data. This research technique can portray different social contexts and is therefore particularly fruitful for the study of the shame–blame complex. By combining these methods, parents' perspectives can be explored

during interviews to shed light on the more internalised dimension of shame, whereas interactions can be analysed through shadowing to explore the more external dimension of blame. This combination of research techniques therefore aptly positions this study to address the interplay between the shame and blame logic within parents' experiences.

Interview transcripts and field notes were manually coded and thematically analysed following the Template Analysis approach (Cardano, 2020). I applied an initial template to the texts, based on existing literature and on the interview guide: felt stigma, enacted stigma, labelling, stereotyping, separation, status loss, discrimination, blame, genetic fault, parental responsibility and bad parenting. I iteratively modified and integrated this set of coding categories during the analysis.

ETHICS AND POSITIONALITY OF THE RESEARCHER

As far as procedural ethics (Guillemin & Gillam, 2004; Scavarda, 2021) is concerned, ethical approval was not required as it is not compulsory for sociological research in Italy. Nevertheless, the local health department, the researcher's doctoral committee, and university department reviewed and agreed to the research project. I discussed potential ethical risks of participation with psychologists and neuropsychiatrists and together concluded that participation did not pose particular risks to the interviewees and might actually provide an occasion to reflect upon their experience. Transcripts were de-identified and fieldnotes anonymised. All names are pseudonyms. All interviewees received the informed consent form, which explained the goals of the study and the use of data (only for research purposes).

As far as ethics in practice (Guillemin & Gillam, 2004; Scavarda, 2021) is concerned, I (a young woman) was not initially familiar with Down syndrome. To learn, I spent several months as a participant observer in a day centre targeting people with Down syndrome. Through this fieldwork experience, I got to know and build trust with some of the people I later interviewed. This experience also crucially shed light on my own stereotypes about Down syndrome, based on scientific knowledge of it. It also helped me design the research methods (for example, the interview guides) in a more appropriate way (Scavarda et al., 2021). I reflected upon my positionality within the research process, as well as the impact of the participation on parents, children and young people/adults in the study, especially the family I shadowed (see, for more details, Scavarda, 2021). As a prospective mother myself at the time, I was able to create an empathic bond with parents, allowing them to share the most contradictory aspects of their biographical experiences. To analyse my emotional involvement in the research activities, I maintained a diary where I reflected on my fieldwork experience. The impact of the research on the participants was carefully monitored through debriefing moments at the end of each interview and shadowing session (Scavarda, 2021). None of the participants expressed discomfort or gave a negative evaluation of their participation in the current research study.

RESULTS

How shame is converted into blame

The interviews and the shadowing session yielded several illustrative examples of how (courtesy) stigma and shame related to having a child with a cognitive disability, namely Down syndrome, is turned into deviance. An ontological condition for which both the person and their parents are not held responsible is thus turned into a moral deficit for which parents are blamed. The blaming process is based on stereotypical knowledge about Down syndrome as a difficult and genetic condition. This knowledge emerges through technologies of domination (Foucault, 1984) and

discourses of family tragedy and reproductive fault. As further explained, shame and blame are often intertwined in a 'shame-blame' complex in which they strengthen each other.

A 'family tragedy': Down syndrome as a difficult condition

During interviews, many parents recalled stigmatising episodes during which the presence of the child with Down syndrome was represented by strangers, as well as family members, as a 'family tragedy':

It was the National Down Syndrome Day, we had a chocolate booth and a couple approached us, [saying] they were sorry for the tragedy

(Father of a 16-year-old boy—Filippo-)

What bothers me the most is the pitying attitude people display towards young people with Down syndrome and their families, just like: 'Poor people'. It looks like a tragedy

(Father of a 25-year-old young man—Alberto-)

To some interviewees, this view of disability as a family burden has a religious aspect: to test parents' trust, they have been chosen to testify to God's suffering. Most of the interviewees refused this Catholic perspective. This refusal could be ambivalent: Filippo's father, while firstly criticising it, assumed this shame-filled attitude at other times, by asserting that he could understand the pain experienced by Jesus Christ on the cross through his family's experience with Down syndrome.

The biomedical paradigm predominates in interviewees' accounts. The presence of a child with Down syndrome is commonly perceived as a 'family tragedy' because it would imply a long-lasting care-giving burden and thus an obstacle for social activities. Care-giving activities are firstly related to anticipated health issues of people with Down syndrome: hypotonia, possible intestinal, heart, thyroids, visual and hearing problems, and a higher risk of having coeliac disease or developing obesity:

A friend of mine exclaimed: 'How many check-ups do you have to do each year? How unlucky you are! So little time to do anything else!'

(Father of a 8-year-old young boy—Michele-)

Interviewees reported that friends and family members supposed that the need to take a child to many doctor's appointments to monitor his/her health status would put parents under stress. This strict schedule of doctor's visits, along with the presumed lack of autonomy of people with Down syndrome, could prevent interviewees from full social participation. These assumptions could be related to stigmatising behaviours, like friends and family members excluding interviewees' families from trips, holidays and social occasions:

The father of her schoolmate affirmed, with a sympathetic tone: 'I presumed you would not come to the mountain hike. It's too intense for Giorgia, isn't it? But for you also! I mean, considering her sluggishness and lack of autonomy'

(Mother of a 12-year-old young girl - Giorgia-)

The attitude reported above represents the first form of ableism reported in the interviewees' accounts: he presumed that people with Down syndrome have reduced physical abilities and autonomy in everyday life. According to this line of thought, parents are forced to limit their social life consequently.

Secondly, assumptions about care-giving burden emerge related to parents' involvement in therapeutical interventions aimed at supporting the child with Down syndrome's slower cognitive development. Not only speech therapy and occupational therapy, but also specific methods like the Doman-Delacato technique—a rehabilitation therapy for patients with cerebral palsy and brain damage which has been extended also to people with Autism (Cascio, 2015; Neurol, 1968)—entail extensive therapeutic activities within the family home. In what follows, Federico's father clearly illustrated how he internalised this cultural and neoliberal expectation:

It is a slower process, and you have to take care of him constantly. This is because today he learns something, tomorrow he will forget it. You've got to keep him going to make sure that he does not regress. You should assist each developmental stage
(Father of a 3-year-old boy—Federico -)

Moreover, the belief that Down syndrome is not necessarily accompanied by learning difficulties—contrary to the clinical and epidemiological evidence—results in the assumption that their cognitive development is dependent on parents' ability to both find specific interventions and replicate them in the home setting. Interviewees, specifically if their children are toddlers, often accepted this task. As Alessandra's father explained:

My parents asked me how severe the cognitive delay was. We did not know, and we still do not know. She has potential abilities, that could be maximised or not, just like every other child. It is up to us as parents to let her achieve her best results
(Father of a 3-year-old girl—Alessandra -)

In contrast, Marta's mother's interview shows how some mothers perceived the pressures to help their children maximise their skills as almost unbearable and inappropriate. Marta's mother was both anxious about providing her child with the appropriate leaning stimuli and nervous because she could not enjoy their time together. These complex feelings resulted in a mental breakdown, from which she recovered only when Marta got into the day care centre:

I was the mum, not the therapist, and I had a breakdown because healthcare professionals and family members always expected me to stimulate my child. I was wondering whether I could live a normal life with her. But I was also conflicted because I was unsure if I had done enough for her. "Today she played, she crawled, is that enough?" Then I took her to the day care centre and it went better, I did not feel so restless trying to do more and more
(Mother of a 10-year-old girl - Marta -)

In this way, the enacted shame for not having a child with the so-called 'standard cognitive and physical abilities' is turned into the enacted blame for not having helped him to develop them. It is widely internalised as felt blame by interviewees, as the previous extracts illustrate.

The 'reproductive fault': Down syndrome as an avoidable condition

Raising a child with Down syndrome is commonly portrayed as a challenging task, inevitably imposing a burden on parents. The underlying assumption is that the birth of a child with Down syndrome is a negative and unintended event, the second form of ableism expressed in parents'

accounts. Parents are therefore expected to avoid the risk of giving birth to a child with this condition or to regret their birth if the genetic condition was not previously identified.

All the interviewees, particularly mothers, reported pressures by both health-care professionals and family members to do the Triple Test exam. This exam is a blood test performed during pregnancy to screen for possible chromosomal disorders and neural tube defects. Interviewed mothers who had a positive result, especially if they were aged 35 and over, often reported health-care professionals prompting them to undergo amniocentesis, a diagnostic test which entails a risk of miscarriage. In this way, a mother's shame for having a 'defective' child is thus converted into blame, owing to the general belief that Down syndrome is associated with a mother's age. The latter assumption is based on scientific evidence, because the probability of having a child with Down syndrome is higher for women aged 35 and over. Public opinion and health-care practitioners can treat this probability as a rule, thereby reframing the birth of a child with Down syndrome as an avoidable predicament. This powerful discourse can be twofold: firstly, it may encourage a mother's sense of guilt for having a child at an older age; secondly, it refers to the rhetoric of a controlled pregnancy to prevent problems, enclosed within the ideal of the 'good mother' (Hays, 1996) but extending also to fathers. The enacted blame is often internalised into felt blame by both parents:

We felt guilty because we did not do a prenatal exam, and because we were old parents. The paediatrician, while examining our child, cried out: 'You gave birth to a child, at your age? Why didn't you take any birth control measures?'

(Father of a 19-year-old boy—Marco)

In this excerpt, the paediatrician's reaction is related to the idea that the birth of a child with Down syndrome is a mistake made by the parents, for which they are fully responsible. This set of beliefs and attitudes created a new kind of parent blame that attempts to position parents as spoiled.

Four interviewed mothers aged 35 and over refused the Triple Test exam, mostly because they would have continued the pregnancy regardless of any birth defects. Their family members framed the women's behaviour as risky because they wanted to know in advance if the child ran the risk of congenital problems. A diagnostic exam was, therefore, perceived as the appropriate action.

I did not want to know if my child had problems. I would still have kept it. So I refused the Triple test exam, but my mother was shocked. She shouted: 'Are you crazy? And if he has Down syndrome?' My mother-in-law also did not understand why I did not want to know it in advance and possibly take appropriate actions.

(Mother of a 15-year-old boy—Matteo)

In addition to family members, health-care professionals may also fuel the parents'—and, particularly, the mothers'—blame. Interviewed parents often claimed that health-care professionals took for granted their willingness to undergo amniocentesis and evaluate a possible abortion. Five parents, however, decided not to perform an amniocentesis, even after a positive result of the Triple Test exam. Family members and health-care professionals judged this decision to be irresponsible because it exposed the couple to the risk of having a child which does not conform to normalcy. An interviewee described her interaction with health-care professionals as follows:

The Triple Text exam returned some suspicious foetal measurements; they told me they had made an appointment for the amniocentesis, without my permission. I was furious; we did not want to do this exam, even though I was 41. [...] My gyn sent me

to * Hospital, where there were many genetic counsellors, [and] they asked me if I was sure about having the baby. They said: 'Do you know how hard it is raising a child with Down syndrome?'

(Mother of a 6-year-old boy—Nicola)

This excerpt shows that health-care professionals can reinforce the stereotypical view of the birth of a child with Down syndrome as a tragedy for the family by highlighting the presumed difficulties implied in raising him/her. Moreover, in the interviewees' accounts, both geneticists and gynaecologists sometimes predicted the onset of health problems that may not necessarily occur because they are only probable and not inevitable:

I did an amniocentesis, [and] my gynaecologist communicated the result to my husband by phone. We were shocked, and then he told us that we could have an abortion abroad or abandon the child at the hospital. He described multiple possibilities and he specified that it was our choice. We decided to keep the baby, but our family members did not entirely agree with us; they expected us to get rid of the baby. However, Giorgia's birth was a relief because all the predicted problems—hypotonia, reflux—did not occur

(Mother of a 12-year-old girl—Giorgia)

Giorgia's mother emphasised the effects of ableism. When faced with a prenatal diagnosis of Down syndrome, both family members and health-care professionals suggested two options: abortion or abandonment at the hospital. This option is given to parents who do not intend to recognise their child. Most family members and health-care professionals were often surprised at the parents' positive reaction to the prenatal diagnosis of Down syndrome or its discovery after the birth of the child. The latter occurs when the condition is not detected through prenatal screening, not only when the parents refused it but also in other situations such as receiving a false negative Triple test result, or not being offered the Triple test because mothers were under 35 years of age. In these cases, others expect parents to react with denial, anger or grief to what they perceive as an intrinsically negative event. If parents accept their child as they are, they are considered exceptions and receive compliments from some health-care professionals, as the following excerpt shows:

The midwife was worried about my reaction because there were many cases of abandonment or attempted suicide. A few days after, she entered my room and affirmed: 'I have never met a couple of parents who face the birth of a child with Down syndrome with such serenity.'

(Mother of 4-year-old child - Daniela -)

The midwife expressed a somewhat pitying attitude and fostered the mother's shame by asserting that parents often respond negatively to the birth of a child with Down syndrome. In the case of Daniela's mother, however, enacted shame is not internalised and converted into felt shame. Instead, as her mother affirmed during the interview: 'I feel lucky to have her' (Mother of a -year-old child, Daniela).

Strategies of resistance to the shame-blame complex

Parents of children with Down syndrome resisted both the shame-blame complex of the 'family tragedy' and of the 'reproductive fault' in various ways, through everyday discourses

and practices. Firstly, some participants contradicted the ableist belief that a child with Down syndrome implies a substantial care-giving burden and a limit for family's social life:

He has NEVER gotten in our way. We have always travelled, gone on holidays, and our social life has never been limited by him. No more than any other child. Samuele has no walking difficulties, therefore he could do whatever we proposed

(Mother of a 25-year-old-young boy—Samuele -)

Secondly, many interviewees opted for missing some of the check-ups included within the follow-up protocol. The decision to flexibly apply the schedule not only saved families time, but also highlighted their children's good health status and the uselessness of the screening tests and monitoring visits. This resistance strategy, enclosed within everyday activities, is described in the following extract from fieldnotes, taken from one shadowing session:

Veronica [Matteo's mother] sits down and picks up the cup of coffee. Then, she looks her friend Manuela in her eyes and affirms: 'You should always book all the tests, you often have to call several times, it is exhausting. It is a waste of time. I have forgotten to call them back and he has missed some appointments. Otherwise, we're a slave to them!'. She lays her cup down on the tray and adds: 'He has never had health problems and we do not feel like it is necessary to do all these medical follow-ups. He has perfect health; he has never even taken antibiotics'.

(Mother of a 15-year-old young boy - Matteo -)

Interviewed parents modify and refuse not only the medical follow-up protocol, but also the framework of exercises and activities included in therapeutical programs. Most of the interviewees chose not to apply the Doman-Delacato model, after carefully assessing it. As Mauro's father pointed out, they expressed the fear of jeopardising their children and family's serenity by exposing them to a strenuous training with inconclusive results:

We refused the Doman method because it jeopardised his and our serenity. It was too stressful, and it was not consistent with our performance expectations. We accept what he gives to us and what he can do. We do not want him to excel, but to take advantage of his relational talents. We tried to bring out his potential by giving him numerous opportunities. But without forcing him. There are some limits

(Father of a 26-year-old man - Mauro -)

Mauro's father highlighted the importance of encouraging children's growth without forcing it. He maintained that he accepted his child's own talents, mainly relational abilities, and thus he rebuffed the blame for not providing enough stimuli for his cognitive development.

Interviewees also resisted the blame for irresponsible reproductive decisions in two main ways. Firstly, some parents portrayed the birth of a child with Down syndrome a contingency, just one of the many risks to which future parents expose themselves when they decide to have a baby. This argument counteracted the ableist belief in the possibility to avoid the condition:

It is a game which starts when you decide to become a mother. Accidents may occur.
Foetal distress or a birth complication

(Mauro's mother)

Secondly, some parents highlighted the dimension of choice, refusing to internalise the feeling of guilt for having exposed themselves to the risk of having a child with cognitive problems. Veronica and Luca—the parents of 15-year-old Matteo, the boy with Down syndrome whom I shadowed for a week—were highly sceptical about prenatal genetic testing, particularly exams aimed at analysing the genetic origin of the disorder. In the following extract, Veronica described how her parents pushed her to do genetic testing during her second pregnancy and how they felt anxious about the result:

I had the worst experience with his little sister: we did the prenatal genetic testing, but the result was taking too long, and we actually received it after her birth. My parents were puzzled; they wanted me to at least do the amniocentesis. They told me that the risk [of having a disabled child] was too high. I refused to do it, as I did for Matteo, so they went to Lourdes [laughing].

By laughing at her parents' anxieties, Veronica refused to internalise the blame for her 'irresponsible' reproductive choice. Moreover, Veronica and Luca often stressed Matteo's lack of physical problems. Thus, they framed Matteo's healthy and athletic body in such a way as to portray him like any other child, and defend their choice:

Father: "Our parents questioned our choice because they were worried about Matteo's health problems. We replied that it depends on the situation. As a matter of fact, Matteo plays tennis and does sports. He has a very athletic body, [and] he is good at tennis. He has no problems at all".

Mother: "We were absolutely right".

Veronica, again, refused the stereotypical view of people with Down syndrome as unhealthy and difficult by emphasising the dimension of choice; hence the enacted shame, in this case, is not internalised and converted into felt shame. However, Veronica and Luca failed to escape from the grips of the shame-blame complex. This strategy of normalising Matteo's situation exposed Veronica and Luca not only to their parents' concerns about the possible difficulties related to raising a disabled child, but also to the blame for giving birth to a child with a disease that could have been detected through prenatal testing, as the following episode—taken from fieldnotes—highlights:

Veronica, Matteo and I are at the local health unit, waiting for the neuropsychiatrist. Veronica is speaking with the secretary, explaining to her that the visit is scheduled in 15 minutes and is a routine check-up. She ironically adds: 'We do not need it. He has just took his middle school exam, and he was better at this than some of his classmates.' The secretary stares at Matteo with a surprised expression. Matteo smiles. She seems a bit annoyed and rashly points to the door of the neuropsychiatrist's office. Then we sit down near the neuropsychiatrist's office door, [and] Matteo loudly starts singing a song from the Disney movie *Aladdin*. Veronica laughs. The secretary approaches her, whispering: 'Madam, did you know that it is possible to do an amnio?'

DISCUSSION

Interviews with and observation of parents of children with Down syndrome show that they experience both courtesy stigma/shame, because of their connection with a disabled child, and deviance/blame for having given birth to a child with a detectable condition.

As far as the courtesy stigma/shame is concerned, parents of children with Down syndrome are often pitied for their family tragedy. This pity labels their situation and separates them from the rest of the population. In this sense, courtesy stigma is a powerful weapon (Scambler, 2018) to keep parents at the margins of society, paradoxically expressing compassion rather than hostility or indifference. The compassionate attitude may be a consequence of the Catholic view on disability, widespread in Italy (Medeghini et al., 2013). According to this perspective, disability is a form of suffering people are called to endure as a sign of God's will. While the majority of interviewees refused this conception, some parents internalised it, feeling burdened but also chosen for the task. The medical approach to disability also contributes to the conception of disability as a burden for the family. Raising a child with Down syndrome is stereotypically portrayed as difficult owing to the child's presumed health problems and lack of autonomy in everyday life. Consequently, parents may limit their social life. This is the first form of ableism expressed in interviewees' accounts, namely the inability of people with Down syndrome to participate fully in social and recreational activities due to their physical or cognitive difficulties. According to this line of thought, the exclusion from trips and holidays, like stigma, extends to the other family members (Birenbaum, 1992; Dako-Gyeke, 2018; MacRae, 1999). This assumption is partly based on evidence, in that people with Down syndrome may develop specific health problems or present malformations (Piepmeier, 2021). However, the higher probability becomes a destiny, and the onset of these medical issues is inaccurately generalised to the entire population, as inevitable complications linked to the condition.

Behind the pitying attitude, the second form of ableism reported by interviewees is the representation of the birth of a child with Down syndrome as a negative and unintended event for parents. In line with previous research (Blum, 2007; Sousa, 2011) interviewees are not only expected to limit their social occasions as a result of their children's impairment, but they are also pushed to make substantial efforts to alleviate these impairments. This pressure is partly due to the stereotypical view of Down syndrome as not necessarily related to learning difficulties. This belief is not based on evidence, although it could represent a misinterpretation of the better level of quality of life experienced by people with Down syndrome, compared to the past (urly.it/3tm11). However, it has specific consequences on parents. Interviewees felt pressured to devote a considerable amount of time to finding the appropriate therapeutical interventions and to reproducing them at home. They often mentioned the need to maximise the potential abilities of their children and they assumed the responsibility of doing it. In these ways, they internalised the neoliberal imperative to be 'good parents' (Henwood et al., 2010; Hoffman, 2010) and particularly 'good mothers' (Hays, 1996).

My results, thus, show that the stigma of having a child with a cognitive congenital disability, and the shame attached to it, is turned into a form of moral culpability directed at the parents. The blaming process is based not only on the technology of domination (Foucault, 1984) of the family tragedy, which parents are compelled to fix with a substantial therapeutical effort, but also on the technology of domination (*ibidem*) of the reproductive fault. The current study suggests that mothers are more subject to blame than fathers, in line with the intensive motherhood approach (Hays, 1996) that, although being extended to parents, has the most demanding moral consequences for mothers. Mothers are still the primary carers of their children in Italy and held most accountable for reproductive decisions. In the interviewees' accounts, then, the 'good mother' should ensure optimal health outcomes for her children, both by providing them with the best available treatments, in line with the 'warrior hero model' (Sousa, 2011), and by making responsible reproductive choices. The latter include screening tests during pregnancy, which are expected to prevent the birth of a disabled child. Thus, women over 35 years old who

refuse to do prenatal testing are deemed responsible for giving birth to an unhealthy foetus, which may imply costs for the State or themselves (Rose, 1990), especially when the condition is detectable, like Down syndrome. If the screening tests return a diagnosis of Down syndrome, parents are often pushed to choose between abortion or abandonment at the hospital because of the health problems envisioned by health-care professionals. The reaction to the diagnosis is expected to be denial, anger or refusal; embracing the condition is considered an unusual response (Piepmeyer, 2021).

The practices and discourses of resistance to these shaming/blaming processes vary from reframing cognitive disability as a contingency or a choice. The contingency strategy frames Down syndrome as a consequence of an event which may occur during pregnancy, childbirth or childhood. In doing so, it extends the category of cognitive disability beyond congenital conditions, considering it as one among the possibilities which may occur in every family at every stage of their life course (Manago et al., 2017; Scavarda, 2020a, 2020b). For this reason, check-ups are not strictly essential and therapeutical interventions, if highly structured and challenging, may be refused. In line with previous studies (Thomas, 2021), numerous interviewees also described 'ordinary' daily lives and the absence of limits to social occasions.

The choice strategy is represented by Matteo's parents. They resisted the shame of having a 'defective child' by stressing that they actively chose it, therefore paradoxically enhancing the blame for their irresponsible reproductive choices. Interviewed parents, then, seem to be unable to free themselves from the shame-blame complex, because the two dimensions are empirically intertwined. At the same time, most of the interviewees do not internalise it because they affirmed that their child is healthy and that raising him/her is not a difficult endeavour envisaged by both health-care professionals and family members. In line with Alison Piepmeyer's account (2021), many parents frame Down syndrome as part of the diversity of human existence, rather than as something to regret or to wish away, and furthermore assert that their child is just as valuable as anyone else.

CONCLUSION

This article has shown how stigma and deviance are overlapping phenomena in the accounts and experiences of parents with cognitively disabled children. Shame is often converted into blame to comply with social and political objectives (Scambler, 2018; Thomas, 2021): to hold parents with cognitively disabled children progressively responsible for their children's impairments. The pitying and genetic narratives are grounded in principles inherent in neoliberal-ableism (Goodley, 2014). More specifically, they are both inspired by the idea of parents' personal responsibility (Rose, 1992), a cornerstone of neoliberal individualism, for ensuring their children's health and educational outcomes and avoiding risky and inappropriate behaviours, and by the cultural imperative to fit in the category of normalcy. The logics of autonomy and self-sufficiency provide an 'ecosystem for the privatisation of ableism' (Thomas, 2021) in which cognitively disabled people are deemed as difficult and less worthy citizens.

The article shows how stigmatising and blaming experiences are both entangled in everyday interactions, disguised as compassionate or protective attitudes and related to larger structural policies and practices dominated by neoliberalism (Charmaz, 2020). Prenatal and postnatal care are organised to avoid and privatise disability, through parents' 'shame-blame complex'. Thus, the interdependence between shame and blame allows to foster the erosion of disabled people and their families' rights (Charmaz, 2020; Thomas, 2021). Disability is framed as a family affair, thus justifying lower social investments in this field. The message, as reported by one of the

interviewees, is the following: 'You made your bed: lie in it' (mother of a 19-year-old young man—Marco). Disability is thus constructed as a private problem to be solved within and by families.

The results presented here illustrate how the attribution of shame and blame play out in people's everyday lives and shed light on what it means to be 'othered' in the case of cognitive/mental difference and to be refused or marginalised by 'normals' (Scambler, 2020). Although the research focused on one specific condition and one national context, the findings may nevertheless prove useful as they can be extended to mental/chronic illness and, more generally, forms of otherness like ethnicity or sexual orientation and stigmatised groups considered outsiders. Comparative and more extensive studies on the topic are therefore needed to further explore the interrelationships between disability stigma and deviance in neoliberal times.

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CONFLICT OF INTEREST STATEMENT

The author declares no conflict of interest.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

ETHICS STATEMENT

The study is compliant with Italian Ethical requirements, which do not imply the need to receive Ethical Committee's approval in the context of social sciences.

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