

ORIGINAL ARTICLE

Expressivist objections to prenatal screening and testing: Perceptions of people living with disability

Felicity Boardman¹  | Gareth Thomas² 

¹Warwick Medical School, University of Warwick, Coventry, UK

²Cardiff University School of Social Sciences, Cardiff, UK

Correspondence

Felicity Boardman, Warwick Medical School, Gibbet Hill Road, Coventry, CV4 7AL, UK.

Email: felicity.boardman@warwick.ac.uk

Gareth Thomas, Cardiff University School of Social Sciences, Glamorgan Building, King Edward VII Avenue, Cardiff, CF10 3WT, UK.

Email: thomasg23@cf.ac.uk

Funding information

Health Research Authority, Grant/Award Number: 17/WM/0231 01/08/17; The Sociological Review Kick Start Grants; Wellcome Trust Investigator Award, Grant/Award Number: 2033884/Z/16/Z

Abstract

The ‘expressivist objection’ (EO) refers to the notion that using reproductive (genetic) technologies to prevent the birth of future would-be disabled people contain, and express, a negative valuation of life with disability. Whilst the EO has received increased attention in recent years in line with rapid technological and genomic developments, there remains scant research on how EO concerns are experienced and expressed by disabled people and their families, especially within and between impairment groups. Bringing together two studies—one with adults and family members living with genetic conditions ($n = 62$) and one with parents of children with Down’s syndrome ($n = 22$)—we argue that disabled people and their families variously embrace, reject or rework the EO across contexts, and yet also frequently situate it within broad support for reproductive technologies. We present three key factors that mediate responses to the EO: (1) the nature of impairment and its integration within identity; (2) social and cultural contexts relating to disability and (3) the (individual and collective) imagined futures of disabled people. In so

Boardman and Thomas contributed equally to this paper.

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doing, we blend the conceptual architecture of medical sociology and disability studies, arguing that this allows us to accurately illuminate the nuanced responses of disabled people and their families.

KEYWORDS

disability, disability studies, expressivist objection, identity, medical sociology, reproduction

INTRODUCTION

The ‘expressivist objection’ (EO) is a term coined by Buchanan (1996, p. 28) to account for the idea that methods designed to ‘correct, ameliorate or prevent’ disability both presume, and communicate, a negative valuation of disabled people. Whilst EO arguments have been cited by disabled people responding to the treatment and cure of impairment (Shakespeare, 2006), as well as in debates on the continuation or withdrawal of life-sustaining treatment (Boardman, 2019), the primary focus of work on the EO has been on disability prevention through interventions in reproduction (Boardman, 2014). Parens and Asch (2000) developed the idea of the EO to critique prenatal screening/testing practices, particularly when these are associated with the offer of selective pregnancy termination. More recently, however, and following developments in reproductive genomics, EO concerns have emerged in relation to specific technologies and screening programmes, including non-invasive prenatal testing (Kaposy, 2021; Thomas et al., 2021), preconception carrier screening (Dive & Newson, 2021) and human germline genome editing (Hoffman-Andrews et al., 2019; MacKeller, 2021). This demonstrates the concept’s endurance and persistence over time and across technological contexts.

At its heart, the EO argument (when applied to selective reproduction) highlights that the prevention of lives of would-be disabled people (whether through prenatal testing and termination, genetic selection or genetic modification) is objectionable, primarily because selection against disabling traits sends a ‘hurtful message’ to those in society who share those traits (Asch, 2000; Parens & Asch, 2000). Akin to other forms of discrimination, Parens and Asch (2000) argue, a singular trait that is socially devalued (disability) comes to represent the entire (future) person, rendering all other possible features of that individual irrelevant—the disability ‘trumps’ all other possible markers of identity (Asch, 2000; Parens & Asch, 2000). This reduction of the future person to a singular disabling trait is hurtful, Parens and Asch (2000, pp. 13–14) contend, because it sends a message that ‘there is no need to find out about the rest’; the ‘part obliterates the whole’.

For EO supporters, the hurt expressed by and through selective reproduction is sent directly (via reproductive choices) and indirectly through its surrounding practices (prenatal counselling), where negative ideas about disability are rehearsed and recycled (Thomas, 2017; Williams et al., 2002). Reproductive practices are set within a social and cultural context that valorises the use of technological interventions to reduce disability as a signifier of ‘responsible’ parenthood (Lippman, 1991; Markens et al., 2012) and delineates disability as an undesirable trait (Kaposy, 2021; Shakespeare, 1998). As such, the argument that we now live under a form of ‘privatised eugenics’ (Fox, 2018), where disability eradication occurs through private decisions framed and constrained by hostile social conditions, gathers weight (Duster, 1990). Indeed, the

incompatibility of selective reproduction with an equitable, inclusive and fair society is widely emphasised (MacKeller, 2021), as is the paradoxical status of modern contemporary societies, wherein rising support, protections and opportunities for disabled people have emerged alongside the development of reproductive technologies capable of detecting ever-expanding lists of conditions (Navon & Thomas, 2021; Shakespeare, 2006).

Despite the traction that the EO argument has gained, its internal consistency has come under widespread critique both within and outside of disability studies. Malek (2010, p. 219), for example, distinguishes between disvalue of a *disability* and disvalue of a *person*, arguing that the decision to prefer a disability-free future for one's offspring implies a negative valuation of the former, whilst saying nothing of the latter. Indeed, even those sympathetic to EO arguments have acknowledged that decisions to prevent disability do not *a priori* imply negative attitudes towards disability or disabled people (Shakespeare, 2006). Bryant and Shakespeare (2021), by highlighting the plethora of factors that may be factored within selective termination decisions (e.g., socioeconomic status and other children), contend that the termination of would-be disabled fetuses can coexist with supportive and respectful attitudes towards disabled people without contradiction.

Despite these arguments, evidence from empirical studies demonstrate that practices of selective reproduction can, and *do*, produce tangible emotional harms for many disabled people (Boardman, 2014; Boardman & Hale, 2018; Hoffman-Andrews et al., 2019; Roadhouse et al., 2018). As such, the EO needs to be taken seriously in consideration of the harms and benefits of screening programmes, regardless of whether its theoretical premise is accepted (Bryant & Shakespeare, 2021). What is less clear, however, in the EO literature, is how far these ideas come to be accepted or rejected by different groups of disabled people and their families. While some disabled people are particularly clear and forthright in their endorsement of EO concerns as they relate to selective reproduction (Hoffman-Andrews et al., 2019; Roadhouse et al., 2018), others are either resistant (Potrata et al., 2014), produce particular iterations of EO ideas (Boardman, 2019) or raise them only in relatively small numbers (Chen & Schiffman, 2000).

The concept of identity and its relationship to impairment and disability has been highlighted as a possible explanation for this diverse range of responses to the EO across impairment groups (Boardman & Hale, 2018). As Edwards (2004) and Mauron (2015) argue, the weight of the EO rests firstly on distinctions between 'disability' and 'illness', and secondly, on how far these relative states are considered 'identity-constituting' (Edwards, 2004). Whilst few would object to interventions designed to prevent cases of flu or cancer on EO grounds (Malek, 2010), acts to prevent conditions such as cystic fibrosis or Down's syndrome may be evaluated differently. For Edwards (2004), this distinction relates to the understanding of certain conditions as *disabilities*, rather than *illnesses* or *impairments*, with some more readily incorporated into identity than others. Through their explorations of identity with people with different types of impairments, Bogart (2014) and Boardman et al. (2018) argue that both impairment effects and age of onset are important factors in the (non)formulation of a disabled identity. Impairments present from birth (or early childhood) are more readily incorporated into personal identity and are those that onset in adulthood (Boardman & Clark, 2022), which is significant when considering that prenatal and new-born screening programmes typically target congenital (early-onset) conditions. This question of who identifies with their *impairment* or *disability* is critical to understanding EO; for it is when a condition is accepted as part of a person's identity that the synecdoche argument within the EO carries most weight. Prenatal screening and selective termination practices, in this instance, are viewed as not only expressing a negative valuation of the condition identified but also of particular *types of persons*.

Distinctions between disability, illness and impairment, and their intersection with identity, have long been debated in medical sociology and disability studies (Thomas, 2012), although there has been surprisingly few interdisciplinary analyses across them (for exceptions, see: Grönvik, 2007; Grue, 2016; Mulvany, 2000). The generation and perpetuation of disciplinary silos have served political agendas. Much of the early theorising of disability scholars rested on the clear separation between ‘disability’ and ‘impairment’ in order to demonstrate the social origins of the former (Barnes et al., 1996). Medical sociologists, such as Bury (2000), on the other hand, instead conceptualise disability as a direct and causal consequence of impairment, even as it is inevitably socially mediated. Whilst these differences in defining and understanding disability have reinforced boundaries between medical sociology and disability studies, Thomas (2012) has argued that because of the rising acceptance of biopsychosocial models of disability within disability studies and the increasing recognition of the significance of ‘impairment effects’ (Shakespeare, 2006), the divide between the two disciplines is becoming increasingly porous.

It is within such porous spaces that the concepts of the ‘healthy’ and ‘unhealthy’ disabled person (Wendell, 2001) have emerged, which draw on conceptual architecture from both medical sociology and disability studies to understand the complex ways that disability is lived and experienced. Indeed, by acknowledging both the socially constructed aspects of disability as well as the roles of health and impairment in informing the nature and experience of that construction, authors such as Wendell (2001) and Thomas (2012) have paved the way for a more nuanced understanding of intersectionality between the disciplines.

We make use of the hybrid spaces that have emerged between medical sociology and disability studies to explore disabled identities (individual and collective, current and future) as they come to be expressed through EO concerns focused on selective reproduction. We bring together 84 qualitative interviews from two separate studies exploring the attitudes of disabled people and their families towards prenatal screening. Previous literature on screening/testing has demonstrated repeated congruence between the views of disabled people and their family members towards screening (Boardman et al., 2017; Woudstra et al., 2022), suggesting that lived experience of disability has the most significant impact on views towards selective reproduction rather than the means through which it is acquired (Nijmeijer et al., 2020). Through an analysis within and across these accounts, we highlight the range of responses, the level of engagement with EO arguments across impairment groups, and the relationship of these responses to identity. Through analytic comparison and using EO ideas as a means by which to interrogate underlying constructs of identity, health, illness, disability and impairment, we highlight their diffusion across the theoretical constructs set up by disability studies and medical sociology. Finally, the implications of this study, not only for interdisciplinary collaboration but for the way(s) that conditions are understood and appraised in repro-genetic contexts (and beyond), are brought into critical relief.

METHODS

Our presented analysis derives from a comparative qualitative analysis focusing on participants’ perceptions of prenatal screening for the condition they live with (or that their child has). The data were gathered by the two authors conducting independent studies with different participant groups (parents of children with Down’s syndrome, and families and individuals living with inherited conditions), that took place between 2017 and 2019.

Study one

Study one was undertaken by Thomas from July 2018 to May 2019. It involved three modes of data collection: (1) Interviews with 22 parents of children with Down's syndrome (DS); (2) an ethnography of a large congress for people with DS, families and allies/stakeholders (e.g., advocates, professionals and researchers); (3) analysis of textual matter (e.g., newspapers and memoirs). Data presented here are drawn from interviews. Interviewees were recruited via local contacts (personal networks; disability charities/organisations). Eligible participants were invited to take part in a face-to-face interview (lasting between 1 and 2 h). Two interviews were completed by telephone at the request of the participant. Twenty of the participants were in a relationship (10 couples) and interviewed together. Both parents (mothers) interviewed individually were married, but partners were unable to participate. Participants were aged between 35 and 70 years and had children between 1 and 15 years old. Parents were mixed with respect to their backgrounds, educational history and employment status. Whilst it is recognised that talking exclusively with parents (not their children) can silence the voices, and neglect any competing perceptions, of disabled children, this study sought to document the accounts of parents who are frequently on the frontline of navigating attitudinal, material and structural inequalities (particularly mothers). Ethical approval for the study was granted by the Cardiff University School of Social Sciences Research Ethics Committee.

Study two

Study two was conducted by Boardman between August 2017 and January 2019. Data were collected as part of a larger mixed methods study exploring the attitudes of people living with genetic conditions towards different types of genetic screening programmes (preconception, prenatal and newborn). Interviews were conducted with people living with genetic conditions themselves and their family members. However, only the interviews with people diagnosed with genetic conditions have been included in this analysis, with the exception of fragile X syndrome, where family members are included. In total, 62 in-depth qualitative interviews were conducted with people living with thalassaemia ($n = 9$), cystic fibrosis ($n = 11$), spinal muscular atrophy (SMA) ($n = 14$), haemophilia/von Willebrands ($n = 10$), fragile X syndrome ($n = 2$) and their relatives ($n = 16$). Participants were recruited in a variety of ways, including from condition-specific charities/patient research registries ($n = 50$), social media and NHS clinics ($n = 12$). Depending on participant preferences and abilities, interviews were conducted face to face ($n = 24$) over the telephone ($n = 36$) or via email ($n = 2$). Ethical approval for the study was granted by the Bioethical and Scientific Research Ethics Committee and the Health Research Authority (17/WM/0231 01/08/17).

Comparative analysis

These two studies were brought together through a collaboration between the authors who identified similar features and cross-cutting themes (including references to the EO) across their two data sets. Whilst not directly asked about within the respective interview schedules, both researchers found that EO ideas emerged spontaneously: sometimes explicitly, sometimes subtly and under various guises. Whilst both studies explored lived experiences and attitudes towards

prenatal screening amongst those with embodied or by-proxy experience of a genetic condition, these different iterations of the EO provided a rationale for a comparative analysis of the data sets with a particular emphasis on areas of convergence and divergence between them. Whilst Thomas' data set explores the accounts of parents of children with Down's syndrome, Boardman's data set predominantly comprises participants living with a genetic condition themselves. Amalgamating the data sets allowed for a comparison of the presentation of the EO across heritable (Boardman's data) and non-heritable (Thomas' data) genetic conditions, as well as its occurrence across condition groups for which prenatal screening is well-established and the general public relatively familiar (Down's syndrome) compared to those for which prenatal screening programmes have yet to be introduced, and/or around which public knowledge is generally poor (fragile X syndrome, spinal muscular atrophy and cystic fibrosis). Finally, by combining the data sets, the diversity of condition groups and impairment effects included in the analysis was maximised. These ranged from intellectual, behavioural and/or physical impairments, treatable and non-treatable conditions, as well as conditions with wide differences in terms of age of onset and implications for health and lifespan.

After combining the data sets, each researcher independently, and then together, analysed the data by thematically focusing upon the views on, and experiences with, prenatal screening and testing, lived experience of disability and iterations of the EO detailed within these. Meetings were conducted via video call over several months to merge our analyses, discuss differences in analytic interpretation and produce an overarching coding framework. These meetings were useful for recognising points of convergence, contradictions and tensions across data sets while remaining attentive to the specificities of both studies. The dimensions of contrast between the data sets, as highlighted above, were particularly important in driving the analysis and enabling us to explore the contours and contradictions of EO ideas.

FINDINGS

The key findings presented here represent the three overarching themes derived from our converged analysis. Quotes have been selected for presentation from across the data set where they most clearly illuminate the concept under discussion.

Impairment, identity and the expressivist objection

References to the EO emerged spontaneously and frequently across the combined data set. For some participants, negative ideas about the value of living with disability were seen to be communicated *implicitly* through the very availability of screening and testing technologies. Harriet (21, type II SMA) said:

I think the way it's going, you know, with screening...it really tells you something about how we, as disabled people, are being thought of, doesn't it? I mean, nothing says "you were a mistake, you shouldn't be here!" more than a screening programme that stops any more of you getting through.

(Harriet)

For other participants, negative messages about life with disability (a key component of the EO) were understood to be communicated *explicitly* in the practices, information and literature surrounding screening programmes. Jenny, the parent of a child with DS, explained:

There [is] always a leaflet you will find somewhere that unfortunately gives this horrendously negative slant. It's just massively misplaced. I still can't get my head around how we're still at this point after the past few years of discussion with [healthcare professionals about living with DS].

(Jenny)

When sharing their stories about the delivery of a diagnosis, parents of children with DS often criticised the involved health-care professional/s, and the medical profession as a whole, for holding what they perceived as an outmoded, inexact and 'medicalised' account of disability (and DS specifically). When discussing how their child's diagnosis was delivered, Charlotte and Henry, the parents of a child with DS, said:

C: It was medicalised. Here's the physical challenges, here are the mental challenges, here are the medical challenges, et cetera. Because that's their business.

H: Particularly the old-school doctors as well. I've done sessions with students over at [hospital] and while they were incredibly receptive, the doctor...some of the slides he was using, we were like, wow. It was very, very medicalised. Horrendous pictures of children with Down's syndrome.

C: It has to be a balanced perspective.

Pre- and post-birth, parents told stories of clumsy and insensitive deliveries of their child's diagnosis. Given these experiences, concerns were raised by some participants that expectant parents, on receiving a prenatal diagnosis, would be *guided towards termination* (Valerie), fuelled by a perception that having a child with DS assures a life of tragedy and hardship. Conversely, parents described their children with DS in overwhelmingly positive terms and DS itself as a *liveable* condition. This involved directly comparing DS to Edward's syndrome and Patau syndrome, both *very different conditions* (Roger) due to their low survival rates post-birth. This idea was similarly expressed by people living with type II SMA, who directly contrasted their experiences with those affected by type I SMA to demonstrate the way that SMA could be experienced as 'liveable', with direct implications for reproductive genetics. Antonia (43, type II SMA) commented:

Even though they're both forms of SMA...type II, you know, is fine...you can live a perfectly fine life. You'll need adaptations, but it's a perfectly fine life. Whereas type I's don't live past their second birthday, although with new treatments that is starting to change. But yeah I can...understand why parents would want to avoid that. It's very different scenario to be presented with...a baby that won't live. Type II is just a disability, it's just a different way of being a person in the world, whereas type I is fatal. They're almost like two entirely different conditions.

(Antonia)

A distinction between 'liveable' conditions that resulted in disability (such as SMA type II and DS), and conditions that resulted in premature death, illness and/or suffering (as in type I SMA, Edward's or Patau syndrome), was evidenced across data sets with implications for both iden-

tity and the way that the EO was expressed. Whilst SMA types I and II may be *lumped together* (Antonia) under the same diagnostic umbrella in a similar way that trisomies (Edwards/Patau/Down's syndrome) could be, participants were keen to emphasise the differences in presentations and their implications for identity. Whilst 'liveable' conditions were more easily viewed as 'identity-constituting' (Edwards, 2004) or *just a different way of being in the world* (Antonia), those that were associated with poor health and suffering were more likely to be viewed as separate to the self, rendering the EO less relevant. Aman's (50, beta-thalassaemia) view of life with his condition and repro-genetic technologies was in stark contrast to Antonia:

I think people should be forced to stop perpetuating this illness...by carrying on knowingly bringing kids into the world with thalassaemia. It's not fair on the kids who ultimately bear the brunt of that decision. [...] I spend many days and weeks a month sick in bed before my next transfusion comes. I feel terrible, every part of my body aches, and I hope every day that they will cure it. I think things are getting closer with stem cells now...or better yet, stop the disease happening in the first place.

(Aman)

Wendell (2001) describes distinctions between who she terms the 'healthy' disabled and the 'unhealthy' disabled, as a way to capture the various ways that impairment is lived and experienced. Those with stable or predictable impairments, she argues, are more likely to identify positively as disabled, which in turn, impacts attitudes towards disability treatment, cure and prevention. Those whom Wendell identifies as the 'unhealthy' disabled, however, are those for whom impairment experiences may be 'transitory or unpredictable' (2001, p. 24). They may involve suffering, decline, intensive medical treatment and a shortened life expectancy—in other words, more closely resembling what medical sociologists recognise as 'chronic illness'. As both Wendell (2001) and Shakespeare (2006) note, it is these individuals who are more likely to compartmentalise impairment as entirely separate to identity, with consequences for the way prevention and cure, and EO ideas, are aligned with (or not). Niall was 64 at the time of his interview and had been diagnosed with SMA type IV in his early forties. Niall described his early experiences with SMA and how they ultimately impacted his views of selective reproduction:

It's not an easy illness to have. I'd been well, managing to do a physical job on the railways, but I was noticing I was losing ... strength, and I wasn't able to do tasks I could have done easily five years previous and I got sacked ...I was utterly demoralised, a shell, but didn't want to admit it. I'm now at the point I'm in a wheelchair 80% of the time. So to go from being super fit, to this...It's a cruel disease. My personal view is that you should stop it in its tracks, and that's why I'd never have kids myself.

(Niall)

Similar to Aman, Niall viewed SMA not as a 'liveable disability' but as a 'disease' and an unwelcome intrusion into his previously physically active life which, in turn, impacted his perceptions of future lives affected by SMA. Bury (1982), a medical sociologist, used the term 'biographical disruption' to account for the way individuals experience the various losses to self and identity that can accompany chronic illness onset (Charmaz (1983) similarly describes this as a 'loss of self'). Disability theorists, conversely, have tended to construct the notion of disability by reference to oppressive social relations. For such theorists, personal identity is a political

project through which relationships between self, disability and society are explored. However, as Niall's account demonstrates, embodied impairment effects (including age of onset), combined with social conditions hostile to those effects, had a significant role to play in Niall's experiences and ultimately in the way he viewed selective reproduction.

Whilst theories of chronic illness may underplay the political consequences of this (in terms of Niall's ultimate support for selective reproduction), disability theory has historically de-emphasised embodied experiences of impairment as a site of identity negotiation (Shakespeare, 2006; Thomas, 2022). However, data from participants with experience of a wide range of impairments demonstrate the clear links between identity, EO ideas and the nature of impairment. Impairments that involved periods of sickness or 'suffering' (Aman), intensive medical interventions, were life-limiting, and/or had a late onset (Niall), all emerged as factors that could influence personal identification with it, and consequently, the relevance of EO ideas to their lives. However, it is important to note that impairment effects were not experienced in a social vacuum. It is to the social and cultural context of impairment that we now turn.

Social and cultural context

For several participants, the visibility and/or public profile of disability had a significant impact on their daily lives and meant that assumptions were frequently made about their abilities and identities. This was particularly the case for families living with DS, as Roger reflected in relation to Isaac (son):

Having the disability written all over their face is actually sometimes an advantage, because people see Isaac coming down the street, they think, "oh, there's someone probably with [DS]". If you have a child who has autism or Asperger's, then it's not necessarily apparent that they might be different, or socially might be struggling, until they start behaving that way, and sometimes people's reactions [...] to people who look very normal, it's bad parenting so it's bad behaviour. So one of the advantages is that people, I suppose, do cut you some slack.

(Roger)

Whilst Roger's account demonstrates the potential advantages of visible 'disability signifiers' regarding how bodies are 'read' in social spaces, with associated prescriptions for action, other participants, such as Lucas (27, type II SMA), described how these could also impede the acknowledgement of other facets of his identity:

It's that archetypal image, isn't it? The person in a wheelchair equals disability... Practically, people can't ignore the fact that I am half the height of them, I'm sitting down, but it tends to be all they see, you know at least at first. No one would describe me as having dark hair, or dark skin, or brown eyes ... they'd say "that guy in the wheelchair".

(Lucas)

For Lucas, having a visible disability in a cultural context in which disability is prioritised as the 'master category' of identity, informs his ideas about the EO and selective termination for SMA:

You know it's the same principle isn't it? They only see the disability and not what that child could bring to the world that has nothing to do with their SMA. And yeah, assuming their life with SMA would be a bit crap really, but there have been lots of positives to having it in my life as well as the harder stuff.

(Lucas)

Lucas' correlation between the way others read his identity, and how the identity of a foetus might be read in a prenatal testing context, is at the heart of the EO. For Lucas, the emphasis placed on SMA (which he perceived to be viewed entirely negatively by the public), over and above all other identity features, was central to his concerns around selective termination. Contrastingly, parents of children with DS believed a public familiarity with DS—as a visible condition with identifiable 'markers'—benefitted them and their children. Parents praised and largely embraced recent portrayals of people with DS in media outputs. Whilst there are issues with such configurations (Thomas, 2021b), they also welcomed attempts seemingly representing a departure from hurtful historical narratives of disability as tragic and pitiable—and especially in a context of growing prenatal diagnostics. Parents denied that their lives were defined by stigma, misery and modes of exclusion. Rather, parents often commented on the 'normality', or the unremarkability, of public interactions. David and Sarah, the parents of Louis (son) who has DS, said:

David: Most people react very positively and engage with Louis, and of course you know, that's the whole thing with Down's syndrome...

Sarah: ...He is very sociable, so he's always talking to people in the community...He is actually a very positive young man, and he loves an audience, so he loves to make people laugh. He's very positive, but then we are positive...So because he's our genes you'd expect that for the genes, not because he's got Down's syndrome.

Parents talked about their children being familiar to others and, in turn, accepted in their local communities and settings (e.g., school)—attributing this, largely, to a positive public image of people with DS. Here, the (visible) *known-ness* of DS translated to being afforded moments of dignity and positive attention in public spaces. In contrast to an arguably increasingly positive representation of people with DS in popular media, some participants with genetic conditions referenced forms of stigma and stereotypes uniquely associated with their impairment/s that directly impacted how they identified with it. Robbie (51, haemophilia A), for example, recognised how his haemophilia became associated with the widely publicised 'blood contamination crisis' of the late 1970s and early 1980s:

I think there's a bit of a hangover...when we had the blood contamination crisis and everyone got HIV and hepatitis from blood products, you suddenly saw haemophiliacs being lumped in with other people like intravenous drug addicts who also got HIV...I started hiding it more, kept it a very separate part of my life and didn't want to be associated with it, and I still do really. I don't see it as a relevant thing people need to know about me.

(Robbie)

Medical sociologists, drawing on the work of Goffman (1963), have examined how stigmatised (or potentially stigmatisable) identities may be 'concealed' by those who bear stigmatising traits

in order to 'pass'. Robbie, like others, had to decide whether 'to display or not to display, to tell or not to tell, to lie or not to lie, and in each case, to whom, how, when and where' (1963: 42), with implications for how far a trait is accepted as part of self-identity. Others, like Nyasia (20, thalassaemia), highlighted how public configurations of thalassaemia within 'Muslim communities' acted as a signifier of 'shame' and led her to hide her condition and disassociate from it as an identity marker:

[Thalassaemia] can be such a dirty word in Muslim communities, even though it's quite high...rates of it here...It's the same with any disability really, it affects the whole family and how you're viewed in the community. So it won't just be me who might struggle to get married, but my brothers too, won't it? So only my family know about it and it's kept hush hush...I think if it can be screened out it would save a lot of shame and heartache. Not that it's the end of the world, but my life would be easier without it if I'm honest.

(Nyasia)

It is notable that, for Nyasia, the *shame and heartache* associated with thalassaemia was not described in terms of the physical impacts of the impairment, as for Aman, but instead was framed by a social and cultural context that devalued thalassaemia as a stigmatised trait. Her rejection of thalassaemia as a facet of her identity is crucial to understanding her view that it should be *screened out*; the disassociation enabled Nyasia to see thalassaemia as a disease separate to herself, and consequently to imagine her life without it.

Across both data sets, identification with impairment and the articulation of EO ideas was mediated by social and cultural contexts. Participants who perceived stigma relating to a specific disability appeared less likely to identify with it, and consequently with expressivist concerns. In contrast, for others, the way they experienced and articulated the EO was related to a wider positive 'public image' of disabled people (such as people with DS). A (perceived) hospitable social environment made it easier to live/thrive and to follow a familiar script of humanity and value. Parents, in particular, framed DS as a category to self-identify with and to mobilise around, forming a 'Down's syndrome community' to cultivate practical, social and emotional support as well as positive identities for them and their children outside of a deficit model of disability (Thomas, 2021a). This seemingly bolstered support for expressivist critiques of reproductive practices. In contrast, in Boardman's study, several participants highlighted how a lack of 'community' and the existence of stigma contribute to negative life experiences and prompt a separation between sense of self and their condition, reducing the relevance of EO ideas and prompting support for the eradication, or 'screening out', of future lives with it.

Imagined futures

The way that individuals imagined future lives, and generations, with their condition was intertwined with their perceptions of identity and disability in the present. These imagined lives of others were the vehicles through which EO ideas could be affirmed or contested and current self-identities expressed. Whether a condition was heritable was critical to these imaginings; for families with inherited genetic conditions, EO concerns were intimately tied to experiential knowledge, family legacy and future blood lines, which influenced the way they were experi-

enced and expressed. Amanda (44), mother of Charlie with fragile X syndrome, described the fragile X gene as a family trait:

Fragile X boys...they can be so loving too...Charlie is...and for all the problems he does have, bless him...We've all got a bit of that [fragile X] in us, and I do...too as a carrier...I think, shouldn't that be preserved? That trait, I suppose? I find it hard to imagine a world where they've just been got rid of. A world without any Charlies in it is quite a scary one for me. You know, we've all got our problems and issues haven't we?

(Amanda)

Amanda's account demonstrates the way that impairment can be identity-constituting beyond the impaired individual, incorporating other family members as well as unrelated people affected with fragile X conditions (*we've all got a bit of that in us*). As highlighted by Finkler (2001), bonds of kinship can be reconfigured through genetic knowledge, extending beyond the biological family. For Amanda, Charlie became a synecdoche for all future affected lives both within and without the family. By viewing the fragile X trait as bringing positive characteristics (as well as some challenges), Amanda's account highlights how collective and familial identities could coalesce around an impairment and shared genetic trait, both within and across kinship groups. In these contexts, EO concerns became both heightened and deeply personalised. For Amanda, technologies of selective reproduction came to be viewed as not only preventing particular types of families, like her own, but targeting individual family members—of future 'Charlies'.

Although Down's syndrome (DS) is not inherited (a rare exception is instances of Translocation DS), parents of children with DS shared similar views about the value of the condition as a trait impacting how futures were imagined. This was made particularly clear when parents criticised the prospect of fewer people being born with DS as a direct consequence of prenatal screening and testing. Jamie, the parent of Noah (with DS), commented:

Would the world be a better place without Down syndrome? Absolutely not. Because you need to understand the good feelings as well, like the empathy and the compassion, versus just self, self, self.

(Jamie)

Parents' positive outlook involved resisting understandings of the future as one of isolation, sorrow and dependency (Kafer, 2013). Parents were explicitly optimistic and excited for what the future held for them and their children. Linda said:

I'd love to see [Christopher] with a job. He loves cooking. He helps with the washing and things. He loves jobs. I can see him doing something like stacking shelves or in a restaurant...I see him in the service industry...I have the same aspirations for Christopher that in many ways I have for [siblings]: that they have their niche...Whatever they want and they're happy, if that be that Christopher goes for a pint [of beer] on a Saturday afternoon with his brothers, then they go off nightclubbing and he comes home, happy days. That, for me, is normal living.

(Linda)

Parents, like Linda, talked about their children in affirmative terms, sharing their normative ambitions about the future (e.g., their child being employed, living semi-independently, having

friendships and romantic relationships). Connecting with other parents of children with DS, and seeing other people with DS (as positive ‘role models’) in popular media, provided the tools necessary for imagining a ‘disability futurity’ (Bolt, 2022; Rice et al., 2017). Such ‘crip’ (Kafer, 2013; McRuer, 2006) narratives allowed parents to imagine ‘dis-topias’ (Rice et al., 2017, p. 213), which recognise disability as ‘part of what makes us human’ (Kafer, 2013, p. 4) and depart from imagined futures cast in gloomier terms.

Likewise, disabled adults in Boardman’s study cited disability in equally affirmative terms. Evidence of the transformative potential of experiencing disability was described by disabled adults as a means to understand the contribution, and value, of disabled lives. Josh (30, cystic fibrosis) said:

I know people find it hard to see CF as anything other than...terrible. But there is absolutely value to having people with CF and other things, out there in the world. We need that kind of diversity. People with CF have so much to offer the world. They bring a perspective and insight that others just don’t “get”...it’s the kind of perspective that the world needs more of, actually, rather than less.

(Josh)

Josh highlights the positive impact of personal experience with disability and its capacity to shape personality, values and outlook on life. Bauman and Murray (2014) have described this value as a form of ‘disability gain’, and references to such positive outcomes derived from experiences with disability were referenced widely across the data sets that, in turn, impacted the appearance of EO concerns. Even where expressivist concerns were not explicitly shared, there was generally a shared concern about ‘the general “direction of travel” of reproduction and pregnancy, with “screening out” disability increasingly considered as an issue of quality control’ (Shakespeare, 2017, p. 127) and something that threatened to ‘destroy the [DS] community’ (Terry) in the future.

There was clear evidence across the data sets that demonstrated the existence of shared identities and tangible communities that coalesced around shared, positively valued disabling traits—and, in turn, the possibility of a ‘disability futurity’. However, for other participants, a future in which their condition no longer existed was framed entirely differently. For Althaia (44) who was diagnosed with thalassaemia shortly after birth, a commitment to safeguarding a ‘thalassaemia-free’ future was pivotal to the reproductive decisions she made, and how she imagined future lives within her family:

I was about 16 when I made a promise to myself that I’d never pass [thalassaemia] onto my kids, you know, it would end with me. And I kept that promise to my daughters, I did all the tests, and they will need to do the same when they come to have their own. So we will know that our grandkids and great grandkids won’t have this to deal with disease...It’s the greatest gift we can give them.

(Althaia)

For Althaia, the removal of thalassaemia from her family’s bloodline was presented as a form of ‘genetic responsibility’ (Hallowell, 1999), handed down from one generation to the next. In stark contrast to the personal transformation narratives espoused by parents of children with DS, a ‘thalassaemia-free’ future was conversely conceptualised as a ‘gift’ to be bestowed on imagined future family members, demonstrating the conceptual separation of thalassaemia from notions of personal and familial identity.

As demonstrated here, engagement with EO ideas was tied up with participants' imaginings of the future; for themselves, their children and un/related others who shared a condition. For some participants, this imagined future in which their condition was 'screened out' was viewed not only as desirable, but indeed, through the prism of obligation and indebtedness to future family members. However, for others, this prospect was met with greater ambivalence or resistance. Both the impairment itself and experiences of disablement were assigned positive value and unique forms of personhood; experiences and characteristics that were perceived to be under existential threat from screening/testing technologies. Taken together, these data highlight the various ways that EO concerns come to be expressed and experienced through collective, as well as individual, identities and imagined futures.

DISCUSSION

Our data demonstrate a wide range of engagements with EO ideas across a broad spectrum of disabled and across participants with embodied and/or indirect experiential knowledge of impairment. Echoing previous research that has demonstrated similarity in the perspectives of disabled people and family members with regard to screening (Woudstra et al., 2022), this study outlines key areas of congruence between the two groups, suggesting that lived experience of disability is, in itself, more important in the formulation of attitudes towards screening and articulation of EO ideas than the way the lived experience is acquired. We argue that disabled people and their families variously embrace, reject or rework the EO across different contexts, even as this is situated within widespread support for the availability of reproductive technologies and selective reproduction, which suggests a degree of ambivalence (Boardman & Clark, 2022; Mascia & Robin, 2021; Nijmeijer et al., 2020). Conceptual distinctions between disability, impairment and illness and their integration into personal identity are critical to understanding these various iterations of the EO, yet are poorly accounted for within disability studies and medical sociology alone. Here, we suggest the need for an integration of approaches that draws on theoretical constructs from both disciplines as a means not only to capture the nuanced responses of disabled people and their families but also to further advance both fields.

Impairment effects, which were largely neglected in early iterations of a social model of disability theorising, were found to play a pivotal role in the creation of personal and collective identities. Those with relatively stable, early-onset impairments were more likely than those with late-onset, degenerative or fluctuating impairments to identify positively with their condition and consequently raise EO concerns around technologies of selective reproduction. By recognising shared identity with a would-be disabled foetus, these participants understood the use of repro-genetic technologies, and the practices surrounding them, as communicating a negative appraisal of both their impairment and their lives. For those who conceptualised their condition as a 'disease' or 'illness', and as separate to the self, EO ideas held less relevance and so did not appear in participants' responses or were referenced only to be dismissed.

By highlighting these polarised views on the EO across impairment groups depending on its incorporation within personal identity, this study demonstrates the need for greater clarity on the conceptual distinctions between disability, impairment and illness/disease. Medical sociology has traditionally understood these experiences in a framework of 'chronic illness', yet this construct fails to account for the experiences recounted by participants in our study, such as Antonia, for whom SMA was experienced as simply *a different way of being in the world* (Antonia), or

Amanda, for whom fragile X syndrome was perceived to be associated with positive personality attributes. It is here that Wendell's (2001) distinction between the 'healthy' and 'unhealthy' disabled may prove constructive in understanding the various iterations of EO ideas that emerged across impairment groups in our work. By acknowledging the fact that impairments can/do involve illness experiences, but also that impairment and healthiness are not mutually exclusive categories, Wendell combines medical sociological approaches with politicised accounts of disability to draw distinctions between illness and impairment. Within our data, whilst impairments were frequently incorporated into personal identity and translated into EO ideas, impairments associated with illness were not.

Along with the direct role of impairment effects, we have also demonstrated the significance of the social and cultural context of disability to the way that EO concerns are expressed and experienced. Indeed, the social meanings assigned to impairment were found to be as important in determining whether participants identified with both their condition and EO ideas as themselves being impairment effects. Echoing the findings of Bogart et al. (2017), stigma mediated whether participants were willing to identify with their condition or *as disabled*. Those who perceived high levels of stigma typically employed strategies to 'pass' (Goffman, 1963) in their everyday lives, especially when a condition was invisible/concealable and was associated with decreased engagement with EO ideas. In contrast, where participants had access to social support and a sense of community, particularly in a context where a condition was 'visible' and seen as positively perceived by members of the public, EO ideas were more pronounced. Whilst parents of children with DS, for instance, recognised structural obstacles that impeded their child's lives (Thomas, 2021a), they also highlighted the way their own support networks, little stigma and affirmative configurations of DS in popular media and their local communities allowed them to see living *with* disability as a valued/valuable way of being and a vital aspect of their identity.

Medical sociologists have traditionally viewed stigma and identity through theories of social deviance (Thomas, 2022), whilst disability scholars have instead focused on the social and political structures that produce both disability and 'disablism'—the 'social imposition of avoidable restrictions on life activities, aspirations and psycho-emotional well-being of people categorised as "impaired" by those deemed "normal"' (Thomas, 2012, p. 37). For disability scholars, identification of the self as disabled is critical to political activism and barrier removal (Goodley et al., 2019). Yet, as our data show, some participants were more likely to incorporate specific illnesses or impairments into their identities than others by drawing on the social framing of that impairment. As Deal (2003), amongst others, notes, a 'hierarchy of impairment' orders more socially acceptable impairments through to those most stigmatised, mediating self-identification with both impairment and disability. By combining the work of both medical sociologists on social interactions and impairment and of disability scholars' work on disability identity as a political project which places inequality, power and oppression at the centre of analysis, the various impacts of the social and cultural context on identity, and consequently engagement with EO ideas, can be better illuminated.

Finally, we have presented the way EO ideas were mediated by participants' reflections on the future. Participants talked about the future in individual, familial and collective terms, identifying bonds of kinship that traversed biological relationships. For families with inherited genetic conditions, EO concerns were intimately tied to family legacy and future blood lines and became uniquely personalised. Similarly, despite DS not being a condition that is ordinarily passed down through family lines, parents of children with DS were nevertheless concerned about the collective futures of their children within a context of reproductive technological growth, and what this meant for their individual children as well as the 'Down's syndrome community'.

Whilst disability studies have done much to disrupt common conceptions of living with disability as tragic and a site of ‘no future’ (Kafer, 2013), the question of how and why disability is identified with continues to pose challenges to the field (Grue, 2016). Indeed, there is evidence within our data sets of the continued relevance of specific impairments to identity politics, confirming the work of others (Deal, 2003; Rhodes et al., 2008). Participants lamented not the prospective loss of all disabled persons via prenatal intervention, but rather the prospective elimination of *Charlies* (Amanda) or people with DS. Grue (2016) contends that non-identification with disability is perhaps unsurprising given that the broad category has itself been constructed in disability studies to show and politicise marginalisation, oppression and exclusion. For Grue (2016), we rarely articulate positive understandings of disability that connote ‘disability-specific positive evaluation’, and examples of disability pride are frequently impairment specific (e.g., ‘Deaf culture’).

It is in this area of identity politics that the impairment-focused work of medical sociologists may be usefully combined with disability studies approaches in order to analyse the political role of collective impairment and illness identities (Mulvany, 2000). Whilst disability studies, particularly within its early renditions, sought to distance itself from a focus on impairment and impairment effects, the continued relevance of impairment, and impairment experiences to identity, has been starkly demonstrated through an analysis of a politicised concept: the EO. We wonder if, as disability is a broad and brittle category (Grue, 2016), medical sociology can help us (in some, but not all, instances) to consider the diverse ways of living, and complex public reactions, perhaps concealed by erecting rigid categories of existence that contain differences in a coherent whole. Doing so may also help scholars to consider, as we have, why some people may not self-identify *as disabled* despite an *impairment* being perceived as such.

Through this analysis, the areas of commonality, and need for a blending of the conceptual architecture of medical sociology and disability studies, have been highlighted, particularly as they relate to understandings of disability, impairment and illness and their various intersections with identities. We encourage scholars who work on reproductive technologies in particular to cross-pollinate and embrace an interdisciplinary approach to understanding these concepts. It is only by doing so that the nuanced responses of disabled people and their families to an ever-changing landscape of reproto-genetic technologies can ever be accurately illuminated.

AUTHOR CONTRIBUTIONS

Felicity Boardman: Conceptualisation; Data curation; Formal analysis; Methodology; Writing – original draft; Writing – reviewing and editing. **Gareth Thomas:** Conceptualisation; Data curation; Formal analysis; Methodology; Writing – original draft; Writing – reviewing and editing.

ACKNOWLEDGEMENTS

FB would like to acknowledge the participants in the Imaging Futures research programme who graciously entrusted me with their stories and reflections. Thanks also to the support organisations, charities and clinics that supported the research. The research was funded by a Wellcome Trust Investigator Award (Grant Number: 203384/Z/16/Z). GT would like to thank the parents who agreed to be interviewed and Julian Hallett at the Down’s Syndrome Association for his assistance to recruit participants. Without their enthusiasm and kindness, this study would not have been possible. Thank you to *The Sociological Review* for funding this project as part of their ‘Kick Start’ Grant scheme. Finally, GT and FB would like to thank the reviewers and editors who provided generous and thoughtful recommendations to improve the article.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions (FB). Research data are not shared (GT).

ORCID

Felicity Boardman  <https://orcid.org/0000-0002-3268-6276>

Gareth Thomas  <https://orcid.org/0000-0003-4959-2337>

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How to cite this article: Boardman, F., & Thomas, G. (2022). Expressivist objections to prenatal screening and testing: Perceptions of people living with disability. *Sociology of Health & Illness*, 1–19. <https://doi.org/10.1111/1467-9566.13559>