**Parenting, disability and gender: on mothers of children with disabilities – disability critique and gender reading**

The past two decades have seen developments in the legal approach to the status of persons with disabilities in both Israel and around the world, revolving around a transition to discourse on rights, full participation, and the prohibition of discrimination. In recent decades, discourse on the rights and identity of this group has broadened in both the academic and civic-activist fields, partly due to the cooperation of advocacy organizations for persons with disabilities and the support of the social model of disability, now a key research tool in this field.[[1]](#footnote-1) Laws prohibiting discrimination against persons with disabilities in multiple countries, such as the as the UN Convention on the Rights of Persons with Disabilities (CRPD), have helped hone an emphasis on society’s role in erecting barriers to the full participation of persons with disabilities and a demand for their elimination.[[2]](#footnote-2) This framework, I believe, currently lacks theoretical and practical consideration regarding the status of parents to children with disabilities, one that can help delineate a set of rights and obligations between the law and state and the parents in question.[[3]](#footnote-3)

In-line with the approach of disability critique and the social model of disability, the term “disability” will herein refer to the social product of a public, legal, economic, and political space historically shaped by and for people without disability, one that reinforces a negative social construction of life with disability. The comprehensive approach of disability critique or critical disability studies has employed critical tools to uncover the social, political, and historical origins of effective disability among those living with disability, and illustrates the experience of disability as the product of negative social construction.[[4]](#footnote-4) Disability critique seeks to divert the discussion from “fixing the person to fixing society,”[[5]](#footnote-5) the latter of which is perceived to be (historically, politically, and economically) responsible for barriers that actuate the disability of those living with disabilities.[[6]](#footnote-6) Accordingly, legal discourse has begun shifting attention from the prohibition of discrimination as the sole content of protecting persons with disabilities, to recognizing obligations to accommodation and environmental adjustment and achieving a more complex understanding of persons with disabilities as a minority and social category.[[7]](#footnote-7)

Unlike the “individual model” that assigns the “problem” and disability to the person themselves, the “social model” uncovers the essence of the negative social construction of disability. It is based on the claim that disability is not a personal characterization, but rather develops within public, social, and political space. In this sense, society is that which disables people with disability.[[8]](#footnote-8) The key distinction between physical, sensory, cognitive, or mental impairment and “disability,” which denotes the shared experience of an entire group, underscores the historical stigmas and political forces that lead to exclusion from public space and the cultural, intellectual, and creative marginalization of persons with disabilities in civil society.[[9]](#footnote-9) It does so by identifying a dominant culture that assumes life with disability is marginal and inferior, and constructs the existence of persons with disabilities as a burden to society as a whole, which views itself as the “normal” community.[[10]](#footnote-10)

The term with which I have chosen to describe the parents of children with disability is “parents *in* disability.” This phrase stems from principles of the critical approach and social model of disability, which center on viewing disability as an experience of exclusion, labeling, and discrimination that does not originate in the unique body, in the impairment or disease, but is rather formed and expressed through encounters with the environment. I will claim and demonstrate the manner in which the parental role of these mothers and fathers, who do not necessary have a physical, cognitive, or mental disability themselves, live and operate in disability in the critical sense of the word.

The large number of families that include children with disabilities, the fact that women are predominantly responsible for treatment and care, the economic and occupational blow to these families, the requisite labor to assemble and realize the rights of these children, the burden of stigma, the effects of negative social constructions of disability – together, these paint a clear picture of consequential injustice. This state of affairs demands a reformed approach.

In this article, I will seek to illuminate the lacking legal status of parents in disability by focusing on mothers in disability and employing the discourse of disability and gender critique. The first part of the article proposes that the fundamental barriers to including the injuries and needs of parents in disability in legal discourse stem primarily from two assumptions, both of which can be challenged. The first is the pervasive distinction between the public and private spheres and the association of parental activity with the private sphere, which is separate and distinct from the public sphere and the judicial tools applicable to it. The second is the predication of judicial action on a tradition of liberal approaches to justice and morality. Through the theoretical analysis below, I will work to discount these bases, as another step toward opening the right door to positive legal intervention in the lives of parents and mothers in disability.

The second part of the article presents the ethics of care as a moral and practical approach that acts as a kind of reverse of the two-sphere approach, and further establishes the legal obligation to parents and mothers in disability. The third part presents a gender analysis of parenthood in disability and the unique socio-legal obstacles facing mothers in disability, and the fourth will offer an examination of motherhood in disability from an additional, extralegal perspective using temporal critique of time as a social and critical concept and tool.

1. **Between spheres and rights**

The classic dichotomy between the public and private spheres, the distinction between “public space” and “private space,” and the legal approach derived from this dichotomy, merit criticism in the context of parents in disability among others. Such criticism stands to highlight their harmful implications for these parents, whose lives revolve around care for their children and issues of dependency and treatment. Here, I will briefly present my claim that the suitable context for discussing the legal status of parents in disability is critical examination of the two-sphere theory, through feminist and liberal discourse and as part of the issue of the status, anchoring, and implementation of socio-economic rights.

The popularization of the terms “public space” and “private space” is attributed to the critical theory of German philosopher Jurgen Habermas. Approaches that distinguish between “public” and “private” space developed toward the end of the 18th century with regard to middle and upper class populations in western countries.[[11]](#footnote-11) As a result of the industrial revolution, the categorical distinction between “private” and “public” was linked to the gender distinction between men and women, in a manner that reinforced the social concept of two separate and contradictory spheres.[[12]](#footnote-12) The distinction between the “public” and “private,” also called “the great dichotomy,” is widely viewed as a fundamental principle of western thought and a central point of departure for discussions on both ethical and political issues and daily life. “The great dichotomy” is perceived to encompass and generate other significant human distinctions and categories, and therefore draws criticism for the sharp binarism that divides the world based on generalizations.[[13]](#footnote-13) Although the sphere theory has been criticized from economic, feminist, and additional perspectives in recent decades, its distinctions, the concepts that have been internalized by western discourse, and the fundamental dichotomy it represents, have retained substantial power.[[14]](#footnote-14)

The public sphere is predominantly described as a space of productive employment, money, politics, and influence, and one inherently linked to different aspects of law, justice, rights, and morality. The private sphere is situated within the intimate space of the home and family, the central space of women. This sphere encompasses personal and private issues and is a non-productive space dissociated from political, economic, and moral contexts.[[15]](#footnote-15) Clearly, no natural criterion distinguishes the “private” from the “public.” This is an arena strictly influenced by social and ideological criteria. Feminist critique exposes this dichotomy as the result of male discourse in neutral guise, which conceals the significant exclusion of women and the ideological partition between women and men.[[16]](#footnote-16) In the “great dichotomy” context, the terms “private” and “public” are used broadly and multi-dimensionally, having been internalized as representative of organizing distinctions in various fields. This is sometimes done without considering the deep meaning and implications of such categorization, and particularly without considering the complex effect of this dichotomy on many aspects of life. In fact, the distinction between “private” and “public” does not posit a single dichotomy, but rather encompasses a host of varying, interconnected contradictions,[[17]](#footnote-17) such as the distinction between civil and social rights, which will be discussed below. In parallel, this binarism also reinforces additional gender-oriented distinctions, for instance, between “work” and tasks that do not constitute “work,” meaning – between efficient, useful, and economically valid work and activities and resources that lack economic value or status. The sphere theory is also linked to distinctions between the worlds of reason and emotion, between groups within the public space and those outside it, and so on.

The justice system is, by nature, a categorical system run and operated according to schematic definitions and definitive distinctions. The law identifies itself with terms such as “public space,” “public servant,” “public interests,” and “economic (public) interventionism,” terms that, knowingly or not, also demarcate the boundaries and objectives of the law. The justice system, which is associated with the public sphere in the historical scheme of “the great dichotomy,” sees itself as precluded from invading the private sphere, or as generally ill-suited to addressing issues in this field. The historically feminine role of childcare and household management has been foundational to the development of the modern western middle class. Care for the other, as well as emotional love, parenthood, fertility, and birth, are associated with the “natural” sphere, which is positioned as inferior to the public sphere – the only legitimate framework for issues of rights, justice, and morality. Parallel to the framing of parental activity as “private,” the negative social construction of disability also positions persons with disabilities and their parents within the private, “feminine” sphere.[[18]](#footnote-18) In other words, one of the assumptions stemming from the separate spheres theory and its gendered nature is that examining concepts such as human rights, moral duties, injury to human dignity, discrimination, or justice, is irrelevant with regards to people and activities situated within the “natural,” “private” sphere that revolves around household, familial, “feminine” space.[[19]](#footnote-19)

Parents in disability are required to invest the majority of their personal, financial, and familial resources in this “private” space in a far more explicit and complex manner than “ordinary” parents do. They are associated with this sphere due to their parental role, the fact that their lives are defined by this role, and their affiliation with the community of disability. For parents in disability, the sphere theory establishes a discriminatory and exclusionary space on one hand, and delays and minimizes legal definition, recognition, and intervention on the other.

One implication of the sphere theory, which is also an important context pertaining to parents in disability, is the discussion on the status and implementation of socio-economic rights. Socio-economic rights are those related to aspects of welfare and everyday needs that also affect economic welfare and income, such as the right to health, employment, education, housing, family, social security, and more.[[20]](#footnote-20)

The claims presented in this study, according to which the legal system must recognize parents in disability and establish a designated legal approach to them, are, as aforementioned, partly associated with discourse centered on social and economic rights. The dichotomous separation of the public and private spheres parallels and reinforces traditions of distinction between civil and political rights and social and economic rights. These traditions represent a perception of civil and political rights as primary, more powerful, ethically superior, and more able to enlist state systems.[[21]](#footnote-21) Civil-political rights are perceived to strictly demand “protection” from the state, or as “negative” rights, in the sense that they do not demand budgetary investment. In contrast, gaining recognition for socio-economic rights as constitutional human rights has been a persistent, historical struggle. Among other things, these rights are linked to claims that “positive” rights demand the state’s affirmative action, which involves a heavy financial burden whose legitimacy is put into question. These distinctions, and the implied claim that socio-economic rights are not “human rights,” merit criticism and even rejection.[[22]](#footnote-22)

Traditional outlooks based on the imprinted inferiority of socio-economic rights have been the subject of considerable criticism. Discussions on the historical precedence of civil-political rights over socio-economic rights, the root of distinctions between negative and positive rights, and their implications and need for their deconstruction, have been conducted in several contexts.[[23]](#footnote-23) This issue is deeply impactful in terms of political, economic, and social issues in Israel and critically important when it comes to legislative issues and the lacking recognition of social rights as human rights.[[24]](#footnote-24) I will note that as the rights of parents in disability have the clear characteristics of socio-economic rights, they are linked to discussions on this lack of legislative recognition and its budgetary cost. At the same time, although the mechanisms required to protect socio-economic rights differ from those required to protect civil and political rights, and although recognizing the former assumes a stronger, broader solidarity than that which underlies the recognition of civil and political rights, socio-economic interests can also be recognized as human rights. As a sound solution, Gavison proposes establishing a bill of rights that includes all categories of rights, while limiting the space of judicial review concerning them.[[25]](#footnote-25)

To summarize this section, it seems parents in disability are an important example of the difficulties stemming from the above-described dichotomies and their categorical nature. As I see it, the needs and rights of parents in disability are situated between the private and public spheres, which is perhaps one cause for their lack of recognition. If subjects related to treatment and care, particularly pertaining to parents and children, are perceived as private issues and an intimate space shrouded by curtains, then the curtains shrouding families in disability are invisible ones. The public space that limits the child, the construction of disability, and structures of economy, employment, and law that do not recognize parenting in disability, place parents in disability in a singular position. For families in disability, activities seemingly associated with the familial space become dilemmas that bear the characteristics of public and political space. The private needs of the children demand a path toward cooperation between formal systems and government bodies. This is perhaps the “parental sphere” of parents in disability, whose legal significance I seek to demand and adjust.

1. **On the ethics of care**

*“Perhaps we know only by comparing, by drawing distinctions from and similarities to what we already know. But when we use our terms of comparison to shut off any understanding of our connections with one another as human beings, we risk becoming something less than human ourselves.”*[[26]](#footnote-26)

In the current section, I will claim that developing the suitable legal approach to parents in disability also demands expanding beyond the liberal justice model and supplementing it with the *ethics of care* as part of a communitarian justice approach.[[27]](#footnote-27) The ethics of care is rooted in cultural feminism and attributes fundamental moral value to the human essence of care for the other.[[28]](#footnote-28) It views interpersonal relationships in general, familial relationships in particular, mutual dependence, community, and social obligation, as moral, ethical, and economic resources that should be promoted and reinforced, including with tools associated with the public sphere, such as the political, monetary, and justice systems.[[29]](#footnote-29) Therefore, the ethics of care also operates as a space of resistance to the great dichotomy and the separate spheres theory and its most deeply rooted implications.

The vital recognition of parents in disability requires exposing the deep impact of negative constructions of disability on these parents, including its internalization. At the same time, parents in disability have a singular voice that relays a perspective of the world through their children’s experience, creating a new, improved, complete worldview. Allowing parents in disability to be heard enables us to portray children living with disabilities as complete individuals and a world unto itself, including in ways that challenge western concepts of independence as a necessary component of humanity and citizenship, and dependence as marginal and outside the norm.

The core of the discourse and principles that shape the ethics of care is the prominent moral power of attention and commitment to fulfilling the needs of a certain individual under one’s care,[[30]](#footnote-30) which stems from the ability to recognize and understand the other even before assuming responsibility for them and addressing their needs.[[31]](#footnote-31) Through the ethics of care, this attention, care, and readiness to fulfill the needs of the other are repositioned as paramount moral considerations for those assume responsibility for another individual. Meaning, feelings of care and readiness to fulfill the needs of dependents should be viewed as central moral considerations for caregivers and be valued and legitimized accordingly. The ethics of care uncovers and seeks to centralize the many significant moral aspects of forming relationships of care and closeness, which enable human beings to develop and live a full life. Among other things, this stems from recognizing human dependence as an inherent characteristic of any human life. Human dependence, whether that of children, the elderly, or persons with disabilities, compels a moral stance on the obligation to respond to said dependence through care and commitment to the needs of the dependent, in a manner that helps them advance and lead a full life. The basic assumptions of this approach challenge the way in which concepts and actions of care are excluded from the moral arena.[[32]](#footnote-32)

The ethics of care helps illuminate that when justice and morality are defined by a liberalist theory that assumes independent relationships between free and equal individuals, dependent and disabled persons are consequently denied the full human rights of choice and dignity.[[33]](#footnote-33) Moreover, within this framework, even the caregivers who treat and fulfill the needs of persons with disabilities, in many ways share this denial of rights and marginality.[[34]](#footnote-34) It is therefore important to recognize that within the familiar system of liberal justice, the status of parents in disability – those whose lives center on providing treatment, care, and mediation for their dependent children – becomes invisible in the political sphere, within which individuals must be perceived as equal and independent.

When Gilligan first coined the “ethics of care,” she called it “a different voice.” She viewed this discourse as a feminine voice, an alternative to the “ethics of justice,” the accepted, valid voice of the moral development model proposed by Lawrence Kohlberg; a voice she identified as masculine.[[35]](#footnote-35) The feminist writings that developed this concept regard the feminine and maternal experience of treatment and caregiving as the foundation of “care” as a way of thought, a rationale, and a moral philosophy.[[36]](#footnote-36) A more detailed analysis of caregiving and its complexity describes it as a combination of practical care for the needs of another – care akin to treatment (“care for”), and emotional care for the wellbeing of another – care akin to consideration, love, and empathy (“care about”).[[37]](#footnote-37) Care as the basic concept of a moral theory must involve both an emotional cognitive aspect and personal intention, as well as active participation in an interpersonal relationship. In this sense, care for a woman or man, a child, an ill individual, an elderly person, or one living with disability, establishes a model for the ethical essence of care. The ethical approach seeks to propose this model as a tool for evaluating and analyzing the moral aspects of human processes and interests. It is important to note that theoretical discourse on the ethics of care, which has deepened overtime, has sought to expand the ethical concept of care beyond gender-related arenas. This process aims to underscore the need to strip away the default social characterization of “care” as “natural,” intimate, and feminine, and situate it within the broader sphere in which relationships, obligations, and duties are seen as components of a moral system.[[38]](#footnote-38)

The “ethics of care” is necessary to gaining a fuller perspective of the moral individual, to creating space for the needs and human dignity of those who are not independent on one hand, those who care for them on the other, and for mutual dependence as a value connecting the two.[[39]](#footnote-39) The perception of citizens as characterized by human relationships of mutual dependence and responsibility, to which every individual is connected, contributes, and depends upon, is a vital component of human existence and dignity.[[40]](#footnote-40) Thus, “care” should be positioned as an ethical principle, meaning – extracted as an ethic from the practices of treatment and care[[41]](#footnote-41)and applied beyond the walls of the home – in the public sphere, as a voice necessary and supplemental to the ethics of justice.[[42]](#footnote-42) Among other things, the absence of this full perception constitutes an additional barrier to recognizing the unique and independent rights of parents in disability.

“Justice as fairness” is described as follows in the prominent liberalist theory of John Rawls, through the discourse developed by Gilligan:

*"… justice as fairness involves seeing others* ***thinly****, as worthy of respect purely by virtue of common humanity, morally good caring requires seeing others* ***thickly****, as constituted by their particular human face, their particular psychological and social self. It also involves taking seriously, or at least being moved by, one's particular connection to the other*”[[43]](#footnote-43)

The above-mentioned concept of “seeing others thinly” is directly related to the former discussion on the legal status of socio-economic rights. One barrier to recognizing these as human rights stems from viewing the individual through a perspective historically rooted in liberal discourse and characterized by a “narrow” view of citizenship. According to Rawls, citizens who participate in the “social contract” must be independent, self-sufficient, equal in ability, and rational in thought.[[44]](#footnote-44) These perceptions form a reality in which human dependence significantly affects the status of caregivers as equal citizens.[[45]](#footnote-45) In effect, those who take part in the “care sphere” are perceived as socially marginal. Their lives are considered “wasted,”[[46]](#footnote-46) just as life with disability is often depicted through the lens of social construction. Therefore, both those who provide treatment or care and those who receive treatment or require care, pay a price that can be described as social stigma. Another integral part of practices and values stemming from neoliberal economy is cultural discourse that empowers the human being as an autonomous, efficient, and effective individual.[[47]](#footnote-47) I would like to underscore that this theoretical and practical structure produces an implicit and explicit social message that is damaging to parents in disability among others. It is a message that whomever birthed an unproductive individual into a neoliberal state – in which individuals are primarily valued according to economic output – should be fully responsible for said individual. I believe this message, and the social outlooks at its core, create an expectation that parents assume the social burden in lieu of the state, which has presumably “lost” the output and contribution of a given individual. In this sense, parents in disability serve as the economic privatization tools of the market state in managing the services, mechanisms, and needs related to children living with disability.

This complex system implements an unjust approach toward parents indisability, one that goes beyond the stances produced by negative social constructions of disability. The modern state, under the aegis of market economy and liberal discourse, washes its hands of the challenges posed by children living with disability. In parallel, state systems legitimize the social marginalization of people with disabilities and facilitate their classification as a socio-economic burden on the community. Simultaneously, parents indisability are expected and even required to dedicate their entire lives to care, treatment, mediation, and advocacy for their children, without designated support, compensation or a voice of their own. In a Canadian study that uncovered the narratives of parents indisability, one mother described the experience as follows:

*"The general population tells you – you're the parent, you're the advocate. You're the only one that will advocate for your child so you've got the guilt on your forehead so my God! If I don't do it…"*[[48]](#footnote-48)

This state of affairs also perpetuates a lack of social legitimacy regarding the voice of these parents. A voice that could convey the personal cost, concessions and sacrifices, along with the expertise, capacities and singular knowledge that enable parents to meet social, economic and legal demands and expectations, to operate as privatization tools for the state, by providing exclusive support to their children over the course of a lifetime. The public and legal system must recognize the unique status of parents indisability in order to repair the systemic flaw and deficient approach described above. The critical approach, on which my demand for recognizing the rights and status of parents indisability is based, seeks to challenge the traditional assumptions, dichotomies and hierarchies that form a set of parallel and interlinked distinctions. A comprehensive, thorough perspective of human rights, which is necessary to recognizing the rights of parents indisability, stands to blur the binary distinction between the public and private spheres, between autonomy/independence and dependence/care, between civil-political rights and socio-economic rights, and between "human rights" and "group interests," respectively. [[49]](#footnote-49)

The concept of viewing the individual through a broad prism, in an in-depth, comprehensive and complex manner – "*thickly*", as an individual and social being, as a citizen and part of a human network of interdependent relationships, is at the core of this approach. [[50]](#footnote-50)

At this juncture, I will note that there are voices within the disability community that criticize and even object to the term “care” in the context of relationships between persons with disabilities and their caregivers and life partners. The term “care” is seen to perpetuate a demeaning view of persons with disabilities as “treatment recipients,” and to undermine their demand for independence, self-fulfillment, and control over their lives. Thus, an additional demand has been made to replace “care” with the concepts of “help” and “assistance.”[[51]](#footnote-51) These critical claims, which have merit of their own, respond to challenges in relationships between adults with disability and their compensated caregivers. When parents in disability are concerned, this criticism and objection becomes less central at the very least, and practically irrelevant. The parental “labor of care” is inherently based on personal, emotional, and moral obligation, without expectation of being remuneration from the care recipient. Parents in disability live in total responsibility, guilt, commitment, and personal sacrifice, which differs from the space in which non-related caregivers work for pay. In every respect, discussing parents in terms of “care” and the ethics of care is more accurate, necessary, and “cleaner” than applying these tools to adults living with disability and their compensated caregivers. Additionally, fundamental to understanding parents in disability is recognizing them as an injured party of the construction of disability and as members of the disability community. From this perspective, the claim that conceptions of “care” have no place in the disability community can be criticized as one that inhibits inclusion of the activity, expertise, and life experience of parents and families in disability as inherent components of disability discourse.

Viewing interpersonal relationships, care, and treatment as ethical spaces with public implications implies the responsibility of the state and justice system, which extends beyond granting liberties and settling disputes. It is a responsibility to recognize the needs of those unable to care for themselves, and as an integral part of this, to recognize their companions, treatment providers, and caregivers. Identifying the ethics of care as a moral principle and situating care and social rights within the public sphere, also generates a different approach to the principles of equality and the dignity of women and men. Kittay writes the following on this subject:

 *“The virtue of care, the asymmetrical, non-reciprocal and par-tial devotion to another’s well-being, which requires that one make oneself transparent to the other’s needs, is a distinctive moral capacity. But if caring is not the same as acting according to the categorical imperative or utilitarian principle, it is nonetheless as peculiarly a human moral capacity as the exercise of rational moral autonomy.”* [[52]](#footnote-52)

The capacity to give and receive treatment and care is thus rendered equally foundational to human morality and dignity as the ability to employ logic and reasoning. Through this prism, equality according to care ethics would define the exclusion of a certain group or population from the space of communal networks, be it education, housing, employment, or any other aspect – as discrimination.[[53]](#footnote-53) This pertains both to persons with disabilities and parents in disability. To include parents in disability in the ethical space of the human, economic, political, and legal community is to include them not as instrumental figures charged with the “bureaucratic labor” of gathering and realizing their children’s rights, but as a group significantly beneficial to society and the economy and one with unique rights. Thus, recognizing the ethical aspects of care and the implications of the negative construction of disability for parents in disability, will not only yield a deeper, more complete social justice, but also the establishment and reinforcement of families, communities, and social relations that can promote an integrated, stable society.[[54]](#footnote-54) Justice and equality for parents in disability therefore demand a complex perspective, through both the “disability lens” and the “care lens.” The “disability” lens will unveil the urgent needs of parents in disability, who carry the burden of negative social constructions of disability and effectively live with economic, professional, and personal disability. The “care lens” will unveil the important link between the needs of parents in disability and human dignity, and enable recognition of the ethical structure stemming from their unique position in the space between their children, and the state and social systems.

1. **Parenthood in disability and gender**

*“The perception that motherhood and politics, motherhood and the public, including public space, the political system, work, and career, reflect internal contradiction, is, of course, false… this contradiction is part of a social construction that contrasts between work for income purposes and motherhood.”*[[55]](#footnote-55)

When discussing the characteristics of parents in disability as a group, it is important to acknowledge that in the majority of families in disability (and families in general) the mother assumes most of the responsibilities relating to the child with disability. Additionally, most women view motherhood as essential to their personal and feminine identity, more explicitly than men view the effect of fatherhood on male identity. The consequent insight is that the implications of parenthood in disability affect mothers more deeply than fathers (although fathers are significantly affected as well, especially those who are caregivers and involved in their children’s lives). Of course, it is important and necessary to discuss issues regarding the division of labor of between fathers and mothers and their legal aspects in families without disability as well.[[56]](#footnote-56) However, when it comes to parenthood in disability, I believe that both the practical and ethical concepts at the core of this discussion as well as the need for models of change and increased gender equality within the family become significantly more exigent and complex. Thus, the theoretical-principle examination of parenthood in disability and of basic perceptions and causes of moral and legislative deficits in this field merits, and even demands, uncovering the gender aspect of this issue as well.

My claim in this context is that the lacking legal recognition of parents in disability is partly rooted in the gender field. Firstly, to discuss parents in disability and their childcare is to discuss activities that are constructed as inherently feminine and positioned within the private sphere. Given this construction and social status, it is difficult for the legal and economic system to identify the injury caused to parents in disability. The gender structure impedes recognition of parental activity as work, and as a resource that should rightfully overlap with the public sphere, which encompasses justice, law, human dignity and rights, and alongside them, the employment arena and the economy – but this is the challenge at hand. In this context, the law must also acknowledge the field of gender inequality in practice and the social dictates that assign the primary burden to women. Currently, legal settlements pertaining to parents and families in disability that do not account for said inequality effectively discriminate against women.[[57]](#footnote-57) This poses a significant barrier to recognizing the need for accommodations toward the meaningful occupational and economic integration of parents in disability, addressing injuries against them in legal discourse, and perceiving their activities as work that has public value.[[58]](#footnote-58) In this regard, the concept of parents in disability as a legal category also demands a more evolved approach to the important task of identifying gender-oriented impediments to its actualization.

A significant socio-gender obstacle that affects the social and legal status of parents in disability is the social construction of the traditional distinction between wife and mother, and work and career. The image of a mother who “goes out” to work; who “wears two hats;” who has “two jobs,” is based on perceptions of marriage and motherhood as the normative life of a woman and “going out” to work as a step beyond this norm.[[59]](#footnote-59) I find that common language structures in Hebrew support this construction as well. A woman “goes out” to work – a deliberate action of “breaking out,” while a man simply “goes” to work as a natural act inherent to the lifestyle expected of him.[[60]](#footnote-60)

Women generally tend to internalize social perceptions of “feminine” and “masculine” roles and characteristics to great extent, and identify firstly as mothers and less so as professionals or part of the employment market.[[61]](#footnote-61) This gender division also contains a historical ethos that influences the social construction of parenthood generally and motherhood specifically within Jewish Israeli society. Since inception, the model of “the Hebrew mother” has carried, in addition to the universal significance of motherhood, unique biblical, Zionist implications of duty to the holy land and the new state.[[62]](#footnote-62) Contemporary Israeli literature, culture, journalism, and discourse also feature prevalent representations of motherhood that imply expectations of complete devotion to infant and child care with utter sacrifice and enjoyment. Despite extensive social, cultural, and economic heterogeneity, contemporary Jewish- Israeli society still regards motherhood as a “collective ethos” that constitutes both a familial role and a national role of expanding the population. The national ethos, which is still central to Israeli culture despite shifts in women and mothers’ status in the western world, carries, among other things, accusatory notions toward forms of motherhood that do not align with the aforementioned image. It thus becomes a difficult barrier for women who experience motherhood in a more complex manner, one that might be labeled “inappropriate.” [[63]](#footnote-63)

An additional barrier related to the gender component of parenting in disability is use of the “choice” element. The social perception, which is also reflected in legal and financial agreements, is that a mother in disability *chooses* to minimize her work life in order to care for her children or *chooses* to leave her job entirely for the sake of parenting in disability; because parents eligible to send their children to government institutions *choose* to keep them at home and assume the burden of care; because parents whose children are referred to special education programs *choose* to fight for their integration into general education and elect to assume the responsibility, expenses, and investment of time and personal resources. Defining these as “choices” stems from an implicit claim that for parents, choices pertaining to their children are personal, familial, intimate. My claim is that these are not, in fact, a matter of free choice.[[64]](#footnote-64) The cultural narrative that describes the choice of mothers in disability to forgo a career, income, personal fulfillment, etc. as a free choice situated within the intimate familial framework, serves a seemingly gender-neutral discourse. In effect, reality, as described above, is divided and gendered via the two-sphere theory, the lacking status of parents in disability, the “good mother” myth, and the economic inferiority of women in the employment market.[[65]](#footnote-65) The social definition of mothers in disability who forgo a career or do not resume full and fulfilling employment as those who have “chosen” to stay at home, also presumably justifies their need to confront the implications of this “free choice” on their own.[[66]](#footnote-66)

In this context, the law must examine how mothers’ primary responsibility for caregiving within families in disability affects the lacking legal status of this parent group, and what form a suitable legal approach to these parents should therefore assume. The law as a social and ideological tool is required and able to effect change in the gender arena for parents in disability – among other things, by recognizing the parental, largely motherly “labor of care” as work that carries public value. The labor of care encompasses different facets of parenthood in disability that demand legal attention, among them the singular expertise of these parents concerning their children, their perception as the state’s privatization tools for instating, fulfilling, and ensuring the accessibility of their children’s rights, along with their representation as the sole responsible parties for the disability and its outcomes.[[67]](#footnote-67) First, recognizing the status of parents in disability as a public resource stands to transfer the mother’s “choice” to remain in the home from the intimate, private sphere to the public sphere, thus expanding the true dimension of this choice. Second, it can lend visibility, terminology, and identity to the complex daily activity of the mother, who will no longer be perceived as “out of work.” Third, positioning the caregiving mother as a contributing factor to family economics, even to small extent, will further her dignity, status, and identity. If the law operates in this manner with the goal of promoting consequential equality, it can also significantly advance the idea that the cultural gap between mothers and fathers, which is intensified and reinforced within families in disability, should not be a necessary implication of gender.

1. **“Time is money”: commentary on the time of parents in disability**

*“Cultural beliefs are like the air we breathe, so taken for granted that they are rarely discussed... No beliefs are more ingrained and subsequently hidden than those about time.”*[[68]](#footnote-68)

In the discussion above, disability critique was presented as a tool for exposing structures that produce the social, economic, and historical marginality of disability, of persons with disabilities, and of their caregivers. I demonstrated how these structures exclude persons and parents in disability from the public space, both by enclosing them within the private sphere and by viewing them as ill-fitting. Physically ill-fitting to a public space that was not designed to contain difference and diversity, and ideologically ill-fitting to a society that promotes ableism and market economy and to an aggressive and survivalist Israeli society. I also claimed that a gender analysis of parenthood in disability is an important tool for exposing a significant barrier to recognizing this group, given that it is characterized as feminine through the prism of the “great dichotomy,” and is predominantly feminine in practice. I view these factors as complicit in the exclusion of parents in disability from the public sphere, and as impediments to their political, economic, and occupational power. In examining legal deficits concerning parents in disability, I have also chosen to present a critical analysis based on the perception of time as a socio-cultural concept.[[69]](#footnote-69) In the following paragraphs, I will discuss the distinction between “feminine time” and “masculine time” as an outcome of the “great dichotomy” and address its significance for parents in disability. Analysis of the temporal dimension exposes an additional barrier to recognizing the legal rights of parents. In the context of parenthood in disability, critical analysis of the temporal dimension is important for its capacity to link between disability critique, gender analysis of parenthood in disability, and literature on time and law, in a way that generates new meaning.

Viewing the temporal dimension as a product of social construction unveils temporal perception as the outcome of historical, economic, political, and social processes designed, among other things, to establish social order, stability, trade systems, and historical continuity. This idea enables a critical perspective that examines the outcomes of time as a social construction, and seeks to deconstruct temporal “givens” whose social essence is nearly invisible.[[70]](#footnote-70) The critical approach to the temporal dimension as a social product is present in critical feminist discourse and is linked to the positioning and reinforcement of women’s status and employment.[[71]](#footnote-71) A feminist reading of the temporal dimension underscores the construction of time as a component of the current and historical subjugation of women. Kristeva, who published her seminal work on this subject in 1979, investigated the development of the feminist movement and in the process, carved the path to critical thought on the temporal dimension. Her claim was based on a distinction between a linear, rational time perception that is viewed as normative and “real” and associated with men, and a cyclical, emotional temporal perception associated with women, motherhood, and devotion. The latter, positioned outside the norm, reinforces the historical exclusion of women from the public, economic, and political sphere, which is largely and mandatorily aligned with “masculine time.”[[72]](#footnote-72) Alongside this, the critical study of the temporal dimension (also called temporal analysis) has become an interdisciplinary research field that produces discursive tools in fields such as sociology, anthropology, economics, and social sciences. I find that there is a direct and significant link between my demand to place parents in disability among those affected by its negative construction, to view their needs as part of the discourse on rights and recognize that their activity extends beyond the private sphere, and between the critical analysis of time.

The prevalent perception of the temporal dimension is rooted in the great dichotomy, and links between the public sphere and linear, objective, and normative time, which stands in contrast to any alternative temporal perception or experience. Linear time perception demands production, progress, and the rational management of resources generally and time specifically, and is known as “clock time,” i.e. normative, masculine time. “Care” is partly perceived as feminine because it does not meet the criteria for activity that has certain status and can be considered part of the normative framework of rational time, production, and public space. Within this framework, parents in disability are placed, at least in some aspects of their lives, outside of normative time processes. The “labor of care” is characterized as “off the clock” activity, as it is not associated with necessarily linear progress or development. The “labor of care” inherently revolves around physical and mental support, around activity whose rhythm and characteristics deviate from the demands of normative, economic, rational time.[[73]](#footnote-73) This characterization surely contributes to positioning caregiving and treatment specifically, and “feminine” activities generally, in the private sphere and outside the discourse on economy and rights. These outlooks, rooted in both society and the law, pose a barrier to the legal standing of parents in disability and the recognition of their rights as legal civil rights.

As we have seen, parallel to the price exacted from these parents by the negative social construction of disability, their association with the private sphere and the perceived inferiority of their rights within public and political space work to damage their legal status. These barriers reflect the manner in which positioning disability and parents in disability on the margins of “real life” is linked to positioning them “beyond time.” This pertains to their supposed incompatibility, at least in terms of their parental role, with modern, industrial, “masculine” time, which reinforces their “otherness.”[[74]](#footnote-74) As aforementioned, this perception is based on both the social construction of disability as a tragedy and social burden, which contradicts production, efficiency, and rationality,[[75]](#footnote-75) as well as the construction of the “labor of care” as activity that cannot be attributed temporal characteristics in economic and public terms. While on the subject of life “beyond time,” there is an additional, notable socio-cultural representation of children with disability that characterizes them, along with being unproductive and lacking status in the public sphere, as existing “beyond time” in the sense that they never mature (“a child with disability remains a child even as an adult”).

1. שגית מור, "בין המשגה פוליטית להכרה משפטית – חסמים במימוש זכויות אנשים עם מוגבלויות" **נגישות לצדק חברתי בישראל** 79, 121 - 123 (ג'וני גל ומימי אייזנשטדט עורכים, 2009) (herein: מור, "בין המשגה להכרה"); נטע זיו, "אנשים עם מוגבלויות - בין זכויות חברתיות לצרכים קיומיים" **זכויות חברתיות ותרבותיות בישראל** 813 (י' רבין וי' שני עורכים, 2004) (herein: זיו, "בין זכויות חברתיות לצרכים קיומיים"); שונית רייטר מעגלי אחווה: לשבירת הקשר בין מוגבלות לבדידות: המהפכה החברתית ביחס לאנשים עם נכויות17 - 40 (2004); Brian John Doyle, Disability, discrimination, and equal opportunities: a comparative study of the employment rights of disabled persons (1995); Ian Byone, Michael Oliver and Colin Barnes, Equal Rights for Disabled People: The Case of a New Law (1991); Tom Shakespeare, *Disabled People’s Self Organization: a New Social Movement?*, 8(3) Disabil. Handicap Soc. 249 (1993); יותם טולוב וארלן ס. קנטר, "של מי החיים שלי? המאבק להשבת האוטונומיה והכשרות המשפטית לאנשים עם מוגבלויות", **מעשי משפט** ו' 45 (2014).

The main principles of the social model of disability will be further discussed in the first section / Section A below. [↑](#footnote-ref-1)
2. One legislative milestone in this field is The Americans with Disabilities Act 1990, 42 U.S.C. § 12101, which centers on the prohibition of discrimination and employment accommodations as well public space accessibility. In Israel, the Equal Rights for People with Disabilities Law was passed in 1998, Open Law Book 1998 1658. The CRPD, adopted by the UN General Assembly at the end of 2006 and effective as of 2008, was signed by Israel in 2007 and approved in September 2012. See Justice Ministry website at: [www.justice.gov.il/Units/NetzivutShivyon/mishpati/Pages/Amana.aspx](http://www.justice.gov.il/Units/NetzivutShivyon/mishpati/Pages/Amana.aspx). [↑](#footnote-ref-2)
3. The CRPD does not actually regard said parents as having specific legal status or practical rights. It mentions “the family” in clause 24 of its preamble, which is strictly declarative, and in Article 23, titled “Respect for Home and the Family,” which recognizes the right of persons with disabilities to start a family and the right of children with disabilities to reside with their families. Within this framework, the sole practical right in the Convention pertaining to parents themselves is to receive “early and comprehensive information, services, and support to children with disabilities and their families,”

in order to prevent the concealment, abandonment, and neglect of children with disabilities (Article 23 (3) of the CRPD, ibid.). The Convention therefore regards the family as a significant unit strictly insofar as it concerns the rights of the children, and this too receives scant attention. [↑](#footnote-ref-3)
4. For leading texts in the field of disability critique see references in footnote 14 above, as well as: Lennard J. Davis, The Disability Studies Reader (1997); Len Barton, *Sociology and disability: Some emerging issues*, *In* Disability and society: Emerging Issues and Insights 3 (Len Barton Ed., 1996).; Tom Shakespeare and Nicholas Watson, *Defending the Social Model*, 12(2) Disabil. Soc. 293 (1997); Tom Shakespeare, *Introduction*, *in* The Disability Reader: Social Science Perspectives 1 (Tom Shakespeare, ed, 1998). [↑](#footnote-ref-4)
5. שגית מור "שוויון זכויות לאנשים עם מוגבלויות בתעסוקה: מתיקון הפרט לתיקון החברה" **עיוני משפט** לה 97 (2012) (herein: מור, "שוויון בתעסוקה"). [↑](#footnote-ref-5)
6. מור, "בין המשגה להכרה", footnote 3 above, pp. 90 - 94; also see: Shakespeare and Watson, *an Outdated Ideology*?, footnote 13 above, pp. 9 – 28; Wendell, The Rejected Body, footnote 14 above, pp. 35 – 45. [↑](#footnote-ref-6)
7. Sagit Mor, *Between* *Charity, Welfare, and Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy*, 18(2) Yale J. Law Humanit.63 (2006) (herein: Mor, *Between Charity, Welfare, and Warfare*). [↑](#footnote-ref-7)
8. Oliver, The Politics of Disablement, footnote 14 above, pp. 78 – 94; Michael Oliver, Understanding Disability: From Theory to Practice 32 – 33 (1996); Shakespeare and Watson, footnote 13 above. [↑](#footnote-ref-8)
9. Oliver, Understanding Disability, ibid, p. 22; Paul Abberley, *The concept of oppression and the development of a social theory of disability*, 2(1) Disabil. Handicap Soc. 5, 5–19 (1987); Shelley Tremain, *On the subject of impairment*, *in* Disability/Postmodernity: Embodying Disability Theory (Mairian Corker and Tom Shakespeare ed., 2002). [↑](#footnote-ref-9)
10. Wendell, The Rejected Body, footnote 14 above; Davis, Enforcing Normalcy, footnote 14 above; Michael Oliver, *A sociology of disability or a disabled society?*, *in* Disability and Society: Emerging Issues and Insights 32 (Len Barton ed., 1996). [↑](#footnote-ref-10)
11. John Williams, *Unbending Gender, Why Family and Work Conflict and What to Do About It* (2000) pp. 19 – 39. [↑](#footnote-ref-11)
12. Women, Culture and Society (Michelle Zimbalist Rosaldo and Louise Lamphere eds., 1974). [↑](#footnote-ref-12)
13. Norberto Bobbio, Democracy and Dictatorship: The Nature and Limits of State Power, chapter 1 (1989). [↑](#footnote-ref-13)
14. חנה הרצוג, "עיוורון מינים? נשים בחברה ובעבודה" **יזמה לצדק חברתי: ישראל אל שנות ה – 2000** (אלקנה מרגלית עורך, תשנ"ו), , presents an analysis of the two-sphere theory vis-à-vis feminist theory and criticizes the assumption that the two-sphere distinction is an objective given, stating that gender inequality is among its byproducts. Herzog demonstrates how the job market integrates the conceptual structure of the great dichotomy, including its gender-related implications. In this sense, the employment integration of women does not yield equality. “Despite the integration of women into economic and political activity, they are still expected to maintain responsibility for the household and children. They are assumed to prefer their familial roles, and in case of conflict between the private and public spheres – the former takes precedence.” Thus, based on the great dichotomy, the education system also reproduces a gender binary approach to higher education, employment, and social expectations, reinforcing women’s inequality. Gaby Weiner, *Feminist Education and Equal Opportunities – Unity or discord?,* 7(3) ) Br. J. Sociol. Educ. 265 (1986); Michelle Fine, Disruptive Voices: The Possibilities of Feminist Research (1992); Jill McLean Taylor, Carol Gilligan and Amy L. Sullivan, Between Voice and Silence: Women and Girls, Race and Relationship (1995), examined the phenomenon of pregnancy and young mothers in the U.S, working to deconstruct its derivation from dichotomous education and public discourse on gender and race. [↑](#footnote-ref-14)
15. Held, footnote 171 above, pp. 12 - 13; Olena Hankivsky, Social Policy and the Ethic of Care (2004), *introduction*; Nancy Folbre, *The Unproductive Housewife: Her Evolution in Nineteen Century Economic Thought*, 16(3) Signs 463 (1991). [↑](#footnote-ref-15)
16. Nancy Freizer, *Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy*, 25/26 Social Text 56 (1990); also see: Joan Landes, Women and the Public Sphere in the Age of the French Revolution(1998); Martha A. Ackelsberg, Resisting Citizenship: Feminist Essays on Politics, Community and Democracy (2010). [↑](#footnote-ref-16)
17. [↑](#footnote-ref-17)
18. Held, footnote 171 above; Hughes, McKie, Hopkins, and Watson, footnote 120 above, p. 262; compare to: Wendell, The Rejected Body, footnote 26, p. 40: The author describes the positioning of persons with disabilities within the private sphere as a component of the social construction of disability. [↑](#footnote-ref-18)
19. Frances E. Olsen, *The Family and the Market: A Study of Ideology and Legal Reform*, 97 Harv.L.Rev. 1497 (1983); Margaret Thornton, *The Public/Private dichotomy: Gendered and Discriminatory*, 18(4) Journal of Law and Society 448 (1991). [↑](#footnote-ref-19)
20. האמנה הבינ"ל בדבר זכויות כלכליות, חברתיות ותרבותיות, (ICESCR) כ"א 1037; ההכרזה האוניברסלית בדבר זכויות האדם http://lib.cet.ac.il/Pages/item.asp?item=7939; [↑](#footnote-ref-20)
21. Yuval Shani offers a chronological historical analysis of the hierarchy between different types of rights. From this perspective, civil rights are “first generation” human rights, while social rights are “second generation.” The Israeli justice system, as he demonstrates and concludes, historically leans toward first generation rights and effectively provides inferior protection of social rights from a normative perspective. See: יובל שני, "זכויות כלכליות, חברתיות ותרבותיות במשפט הבינלאומי" **זכויות כלכליות, חברתיות ותרבותיות בישראל** 305 (יורם רבין ויובל שני עורכים, 2004). [↑](#footnote-ref-21)
22. רות גביזון, "על היחסים בין זכויות אזרחיות-פוליטיות ובין זכויות חברתיות-כלכליות" **זכויות כלכליות, חברתיות ותרבותיות בישראל** 25, 40 - 44 (יורם רבין ויובל שני עורכים, 2004). [↑](#footnote-ref-22)
23. אהרון ברק, "הקדמה" **זכויות כלכליות, חברתיות ותרבותיות בישראל (**יורם רבין ויובל שני עורכים, 2004); גביזון, ibid; גיא דוידוב, "ביקורת חוקתית בעניינים בעלי השלכה תקציבית", **הפרקליט** מט 345, 354 – 356 (תשס"ח); גיא מונדלק "זכויות חברתיות-כלכליות בשיח החוקתי החדש: מזכויות חברתיות לממד החברתי של זכויות האדם" **ספר ברנזון** (כרך ב) 183 (אהרון ברק, עורך, 2000); דפנה ברק-ארז ואייל גרוס, ["הזכויות החברתיות והמאבק על אזרחות חברתית בישראל: מעבר לזכות לכבוד"](http://www.tau.ac.il/law/barakerez/articals/76.pdf) **189 ספר דליה דורנר (2009);** ריקי שיו "'עצרו את המהפכה בלעדי': על השמעתו ומשטורו של שיח הצדק החלוקתי והזכויות החברתיות" **מעשי משפט** ב 185 (2009); זיו, "בין זכויות חברתיות לצרכים קיומיים", footnote 11 above; מור, "בין המשגה להכרה", footnote 11 above, pp. 121 – 123. [↑](#footnote-ref-23)
24. אהרון ברק, "הקדמה" **זכויות כלכליות, חברתיות ותרבותיות בישראל (**יורם רבין ויובל שני עורכים, 2004); גביזון, שם; גיא דוידוב, "ביקורת חוקתית בעניינים בעלי השלכה תקציבית", **הפרקליט** מט 345, 354 – 356 (תשס"ח); גיא מונדלק "זכויות חברתיות-כלכליות בשיח החוקתי החדש: מזכויות חברתיות לממד החברתי של זכויות האדם" **ספר ברנזון** (כרך ב) 183 (אהרון ברק, עורך, 2000); דפנה ברק-ארז ואייל גרוס, ["הזכויות החברתיות והמאבק על אזרחות חברתית בישראל: מעבר לזכות לכבוד"](http://www.tau.ac.il/law/barakerez/articals/76.pdf) **189 ספר דליה דורנר (2009);** ריקי שיו "'עצרו את המהפכה בלעדי': על השמעתו ומשטורו של שיח הצדק החלוקתי והזכויות החברתיות" **מעשי משפט** ב 185 (2009); זיו, "בין זכויות חברתיות לצרכים קיומיים", footnote 11 above; מור, "בין המשגה להכרה", footnote 11 above, pp. 21-23. [↑](#footnote-ref-24)
25. גביזון, footnote 143 above, pp. 46 – 48, 60 -66. [↑](#footnote-ref-25)
26. Minow, footnote 37 above, p. 7. [↑](#footnote-ref-26)
27. For writing on communitarianism and its position within the legal field, see: Sandel, footnote 15 above; Amitai Etzioni, *Creating Good Communities and Good Societies,* 29(1) Contemporary Sociology 188 (2000); Michael Walzer, Spheres of Justice (1983). For an approach by with the ethics of care could merge with the liberal justice model to form a complex and complete line of thought see for instance: Viriginia Held, *The Ethics of* Care, *in* The Oxford Hendbook of Ethical Theory (David Copp ed., 2006); Marilyn Friedman, What Are Friends For? Feminist Prespectives on Personal Relationships and Moral Theory(1993); Annette Baier, *The Need For More Than Justice*, *in* Justice and Care: Essential Readings in Feminist Ethics (Virginia Held ed., 1995). [↑](#footnote-ref-27)
28. Carol Gilligan, In a Different Voice: Psychological Theory and Women's Development (1982). Gilligan was the first to address the claim that women tend to deal with moral issues differently than men, in the sense that they are likely to consider moral issues in terms of personal relationships, care, and emotional involvement with the other, while men tend to consider the rational implications of rules and laws, in terms of separateness and autonomy from the other. [↑](#footnote-ref-28)
29. Virginia Held, The Ethics of Care: Personal, Political, and Global (2006), particularly the second part of the book that discusses conducting economic, social, and legal activity based on the ethics of care as a moral theory; Nell Noddings, Educationg Moral People: A Caring Alternative to Character Education (2002) ;Fiona Williams, *In and Beyond New Labour: Towards a New Political Ethics of Care*, 21(4) Crit. Soc. Pol. 467 (2001) ; Michael Slote, The Ethics of Care and Empathy (2007) . [↑](#footnote-ref-29)
30. Held, Ibid, p. 10. [↑](#footnote-ref-30)
31. Joan C. Tronto, Moral Boundaries: A Political Argument for an Ethic of Care (1993). [↑](#footnote-ref-31)
32. Held, Ibid, p. 10. [↑](#footnote-ref-32)
33. Martha C. Nussbaum, *Rawls and feminism*, *in* The Cambridge Companion to Rawls 488, 511–14 (Samuel Freeman ed., 2003); Martha C. Nussbaum, *The future of feminist liberalism*, *in* Varieties of Feminist Liberalism 103 (Amy R. Baehr ed. 2004); מור, "בין המשגה להכרה", footnote 11 above, pp. 90 - 94; Eva Feder Kittay, Love's Labor, Essay on Women, Equality, and Dependency 79 – 82, 88 - 93(1999) (herein: Kittay, *Love’s Labor*); Allen Buchanan, *Justice as reciprocity versus subject-centered justice*, 19 Philosophy and Public Affairs 227, 230 (1990); Harry Brighouse, *Can justice as fairness accommodate the disabled?*, 27 Social Theory and Practice 537 (2001). [↑](#footnote-ref-33)
34. Kittay, Love's Labor, ibid, pp. 76 – 77. [↑](#footnote-ref-34)
35. Carol Gilligan, footnote 170 above; Carol Gilligan, *Moral Orientation and Moral Development*, *in* Women and Moral Theory 19 (Eva Fedder Kitay and Diana T. Meyers eds., 1987); Tronto, footnote 173 above, pp. 61 – 96; also see a critical analysis regarding the Gilligan-Kohlberg debate in: Owen Flanagan and Kathryn Jackson, *Justice, Care and Gender: The Kohlberg-Gilligan Debate Revisited*, 97(3) Ethics 622 (1987). [↑](#footnote-ref-35)
36. Held, footnote 171 above, p. 51; Ned Noddings, Caring: A Feminine Approach to Ethics and Moral Education 14 – 19 (1986); Kittay, Love’s Labor, footnote 175 above, pp. 30-31. [↑](#footnote-ref-36)
37. Also see: Rannveig Traustadottir, *Mothers Who Care: Gender, Disability and family Life*, 12(2) Journal of Family Issues 211, 216 (1991), which uses interviews with mothers in disability to present the terms “care for” as denoting work and “care about” as denoting love. [↑](#footnote-ref-37)
38. Selma Sevenhuijsen, Citizen and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics (1998); Slote, *introduction,* footnote 171 above; Virginia Held, Feminist Morality: Transforming Culture, Society and Politics223 (1993); Michael Slote, Agent-Based Virtue Ethics, 20 Midwest Studies in Philosophy 97, 101(1995); Nel Noddings, Starting At Home: Caring and Social Policy (2002) 21 – 24. Compare to: Shadmi, footnote 147 above: Shadmi presents motherhood as an organizing principle for a new social order based on “gift economy,” as part of a matriarchal community system. The maternal concept as a social foundation “[extends] beyond discussions on good, bad, biological, or social motherhood, instead unveiling it as a human, social, political, and economic principle, as an alternative culture of ethics and practices… as such, motherhood is not something to believe in but rather something to do, it is a way of life.” (ibid, p. 44). [↑](#footnote-ref-38)
39. Held, footnote 171 above, pp. 62-66; Martha Nussbaum, Frontiers of Justice 96 – 145 (2005)(herein: Nussbaum, *Frontiers of Justice*); Kittay, Love's Labor, footnote 175 above, pp. 83-99; John Rawls, Justice as Fairness: A Restatement 175 - 176 (Erin Kelly ed., 2001), although Rawls “corrects” and writes that obligation toward any human being including those with severe disability should be a given (footnote 59 ibid, p. 176), it is highly questionable whether the term “obligation” refers to justice. [↑](#footnote-ref-39)
40. Kittay, Love's Labor, footnote 175 above, pp. 75-82; Slote, footnote 171 above, pp. 67-83; Held, footnote 70 above, pp. 58 -66; also see: Neta Ziv, *The Social Rights of People with Disabilities: Reconciling Care and Justice* Exploring Social Rights Between Theory and Practice370 (Dafna Barak-Erez and A. Gross, eds., 2007). [↑](#footnote-ref-40)
41. Eva Kittay, *The Ethics of Care, Dependence, and Disability*, 24(1) Ratio Juris*,* 49 (2011) (herein: Kittay, *The Ethics of Care*). [↑](#footnote-ref-41)
42. Tronto, footnote 177 above, particularly pp. 157-180; also see: Michael Fine, Caroline Glendinning, *Dependence, Independence or Inter-dependence? Revising the Concept of 'care' and 'Dependency’*, 25 Aging and Society, 601, 604 – 605 (2005); compare to:

רות זפרן, "זכויות הילד במשפט כזכויות יחס" **זכויות הילד והמשפט הישראלי** 129 (תמר מורג, ed., 2010), וכן: רות זפרן, "שיח היחסים כתשתית להכרעה בסוגיות מתחום המשפחה: מספר הערות על דאגה וצדק" **משפטים על אהבה** 605 (ארנה בן-פתלי וחנה נוה, eds., 2005) [↑](#footnote-ref-42)
43. Owen Flanagan and Kathryn Jackson, *Justice, Care and Gender: The Kohlberg-Gilligan Debate Revisited*, 97(3) Ethics 622, 623 (1987) (author’s emphases). [↑](#footnote-ref-43)
44. Nussbaum 2005, footnote 1818 above,מור, "בין המשגה להכרה" , footnote 11 above, pp. 90 – 94. [↑](#footnote-ref-44)
45. Kittay, The Ethics of Care, footnote 182 above, p. 102; Kittay, Love's Labor, footnote 175 above, pp. 75 – 77. [↑](#footnote-ref-45)
46. Hughes et al, footnote 120 above, p. 267. [↑](#footnote-ref-46)
47. The grip of neoliberalism in Israel also introduced neoliberal discourse, which defines a modern society through “market forces” and the “free market.” A direct outcome of this approach is change in resource and income distribution and the effective increase of civic inequality. [↑](#footnote-ref-47)
48. Jay A. Goddard, Ron Lehr, Judith C. Lapadat, "*Parents of Children with Disabilities: Telling a Different Story"*, 34(4)Can. J. Couns. 273, 279 (2000). [↑](#footnote-ref-48)
49. Ziv, footnote 182 above. [↑](#footnote-ref-49)
50. Compare to: Gavison, footnote 143 above, pp. 47 – 48. [↑](#footnote-ref-50)
51. See: Tom Shakespeare, Help (2000); Jenny Morris, Pride Against Prejudice: Transforming Attitudes to Disability (1991) *Chapter 6*; Jenny Morris, Independent Lives? Community Care and Disabled People(1993) *Chapter 3.* For a response to this critique see: Hughes, McKie, Hopkins, and Watson, footnote 58 above, p. 268; Also see the earlier discussion by Barnes (1992) according to which media depictions of persons with disabilities as a burden to society reinforce a perception of their caregivers and life partners as tortured saints who sacrifice and carry the responsibility, and persons with disabilities as a cause of suffering for those around them. Barnes notes that these stances are based on a socio-economic deficiency that forces persons with disabilities to rely on uncompensated caregivers, particularly women, and renders them unable to actively select and employ their caregivers. Colin Barnes, footnote 123 above, pp. 15-16. [↑](#footnote-ref-51)
52. Eva Feder Kittay, *Equality, Dignity and Disability*, in Perspectives on Equality 93, 111 (Mary Ann Lyons and Fionnuala Waldron eds., 2005). [↑](#footnote-ref-52)
53. Compare to: נטע זיו "אנשים עם מוגבלות ושיח זכויות האדם: סתירה או פוטנציאל לשינוי?" **פרלמנט** 74 (המכון הישראלי לדמוקרטיה, 2012). [↑](#footnote-ref-53)
54. Hankivsky, footnote 136 above, pp. 8 - 29. [↑](#footnote-ref-54)
55. אראלה שדמי, "אימהות: בין תוהו, כשלים, קסם וחזון" **דרך אם** 22 (אראלה שדמי עורכת, 2015). [↑](#footnote-ref-55)
56. Williams 2000 (shifts in the division of labor in the household are slow and women are still considered “naturally” responsible for most housework); Andrea Doucet, *Can Parenting Be Equal? Rethinking the Equality and Gender Differences in Parenting*, *in* What is Parenthood 257 (L.McClain and D. Cere eds. 2013); מיכל פרנקל, דפנה הקר, יעל ברוידא, "משפחות עובדות במשפט הישראלי: בין נאו ליברליזם לזכויות אדם" **עיונים בתקומת ישראל: מגדר בישראל**, 682 (מרגלית שילה וגדעון כ"ץ עורכים, 2011).. There are several legal subjects that merit discussion and point to a need for change in gender equality within the family, which are relevant to families in disability but are not unique to them, such paternity leave, custody arrangements, and more. See for instance: דפנה הקר ורונן שמיר, "'אימהות', 'אבות', 'משפחה': בין אינטואיציה להלכה פסוקה", **סוציולוגיה ישראלית** ה(2) 311 (2003). [↑](#footnote-ref-56)
57. Compare to: דפנה הקר, **הורות במשפט – מאחורי הקלעים של עיצוב הסדרי משמורת וראייה בגירושין** (2008), פרק ראשון. In discussing the possibility of rescinding the “tender years doctrine,” Hacker establishes that a gap damaging to women may form between formal law and presumably natural judicial rhetoric, and a social reality strongly influenced by the “good mother” myth and a clear distinction between mothers and fathers. Also compare to: נויה רימלט, "אמא טובה, אמא רעה, אמא לא רלוונטית: הורות במשפט בין אידאל השוויון למציאות האימהית", **משפטים** ל"ט 573, 581 – 588 (תש"ע) (להלן: רימלט, "אמא טובה, אמא רעה"). [↑](#footnote-ref-57)
58. Compare to: Martha Nussbaum, *Disabled Lives: Who Cares?* The New York Review of Books, Jan 11, 2001 <http://www.nybooks.com/articles/2001/01/11/disabled-lives-who-cares>. [↑](#footnote-ref-58)
59. ענת פסטה שוברט "נשים עובדות, נשים לומדות: ההבחנה בין הספרה הפרטית לספרה הציבורית בראי הספרות המחקרית – סקירה ביקורתית" **מעוף ומעשה** 6 (תש"ס) 45, 48 – 52:

The proliferation of studies on the tension between “home” and “career” in the lives of women is prompted by a social construction that depicts women’s address to the public sphere as a “phenomenon” that merits research. Also compare to:ריאן רנן-ברזילי "הורים א/עובדים: רב מימדיות והפמיניזם החברתי של מעמד הפועלות" **עיוני משפט** ל"ה 313 (תשע"ג). [↑](#footnote-ref-59)
60. לעניין המטען המגדרי של השפה העברית, פרקטיקות לשוניות המנציחות חוסר שוויון וכאלו המקדמות שוויון ולחובת המשפט לנושא זה ראו: שולמית אלמוג, "ואותן השמות עומדים לדורות – על עברית, מגדר ומשפט" **מחקרי משפט** יח' 373 (2002) וכן: שולמית אלמוג, "קודיפיקציה עברית: שפת המשפט ושפת השוויון" **משפט ועסקים** ד' 539 (2006). [↑](#footnote-ref-60)
61. See: Sharon Hays, The Cultural Contradictions of Motherhood 157 (1996); אריאלה פרידמן **באה מאהבה, אינטימיות וכח בזהות הנשית** (1996) 15 – 18. [↑](#footnote-ref-61)
62. In the words of Ben-Gurion: “Increased reproduction is necessary to the establishment of Israel, and a Jewish woman who does not bring at least four children into the world… betrays the Jewish enterprise.” From "איך להעלות את שיעור הילודה" **הארץ** 8 בספטמבר 1967; מצוטט אצל לסלי הייזלטון **צלע אדם: האשה בחברה הישראלית** (1978) 52;; also see: יסמין קיני "תופעה: מסתפקים בילד אחד, ודי!" **nrg מעריב** 7.2.2009 [www.nrg.co.il/online/55/ART1/850/139.html](http://www.nrg.co.il/online/55/ART1/850/139.html), which states the following: “The assumption is that the number of children one births, if at all, is the intimate choice of the woman or the couple, but in Israel the boundary of personal autonomy is breached. In Israel, the number of children one has is a public, not to mention national, issue.” [↑](#footnote-ref-62)
63. See:עמנואל ברמן, "הנסיך המאושר, העץ הנדיב: הפנטזיה של הורות כהכחדה עצמית", **שיחות** 19, 35 (2004); As well as: לילי רתוק, "כל אישה מכירה את זה", epilogue in:**הקול האחר: סיפורת נשים עברית** (לילי רתוק – עורכת) תל-אביב הקיבוץ המאוחד 1994-, where she states: “Due to the dominance of this myth, women have not dared to admit the difficulties they face in child rearing. The image of the good mother, who enjoys committing fully to nurturing her offspring, has been a barrier to women who experienced motherhood in a more complex manner…” – this statement gains even greater significance when discussing motherhood in disability. Also compare to: ק. ארוניס ""הרעלתי את התינוק שלי": עיצוב אופיה ותפקידה של האם הישראלית במסגרת פרשת רמדיה בעיתונות הפופולרית", **עבודת גמר למוסמך בתקשורת ועיתונאות** (האוניברסיטה העברית, ירושלים, 2006). [↑](#footnote-ref-63)
64. Compare to:נויה רימלט, "בין סגרגציה לאינטגרציה: קריאה לחשיבה פמיניסטית מחודשת על שוויון ומגדר בשוק העבודה" **מחקרי משפט** כד, 299 (2008) (להלן: רימלט, "בין סגרגציה לאינטגרציה").

Also see: Anne E. Alstott, No Exit: What Parents Owe Their Children and What Society Owes Parents 49 - 72(2004), describes the framework of parental commitment to children, which is perceived as a space from which there is “No Exit,” and offers an interesting conception of mutual relations between the parents and state. For more on discrimination relating to women’s employment, see: Paula England, Paul Allison, and Yuxiao Wu, Mart Ross, *Does Bad Pay Cause Occupations to Feminize, Does Feminization Reduce Pay, and How Can We Tell with Longitudinal Data?* 36(3) Social Science Research 1237 (2007); Hadas Mandel, *Up the Down Staircase: Women's Upward Mobility and the Wage Penalty for Occupational Feminization, 1970-2007*, 91(4) Social Forces 1183 (2013); Gay Mundlak and Hila Shamir, *Between intimacy and Elienage: The Legal Construction of Domestic and Carework in the Welfare State*, *in* Migration and Domestic Work: A European Prespective on A Global Theme 161 (Helma Lutz ed., 2008). [↑](#footnote-ref-64)
65. I will add that a similar social structure is also applied to other “choices” attributed to women as part of a constructed status-quo suited to masculine society and liberal frameworks. For a fascinating analysis of women in prostitution, see: אלמוג, **נשים מופקרות**, footnote 79 above. On the narrative of “choice” in prostitution and its legal implications, see mainly chapter two:"העיסוק בזנות ודיני העבודה: בין נסחרת לבוחרת". [↑](#footnote-ref-65)
66. Compare to a similar discussion on women’s general status in the Israeli employment market, in the introduction to the article by מיכל פרנקל, דפנה הקר, יעל ברוידא, "משפחות עובדות במשפט הישראלי",

footnote 148 above. [↑](#footnote-ref-66)
67. For more on the labor of care and its characteristics, and labor of care as a public and economic resource, see part B in the current chapter and part D in Chapter Six. [↑](#footnote-ref-67)
68. Robert Levine, A Geography Of Time: The Temporal Misadventures Of A Social Psychologist, Preface xv (1997), examines different perceptions of time in various societies and social groups around the world, with the assumption that understanding the complexity and diversity of temporal experience can lead to a fuller understanding of time as a social concept organized by the human being and used to organize human life. [↑](#footnote-ref-68)
69. The concept of “social time” is attributed to sociologists Sorokin and Merton following their historic article from 1937: Pitirim A. Sorokin and Robert K. Merton, Social Time: A Methodological and Functional Analysis, 42(5) AM. J. Soc. 615 (1937). For a historical view on the development of the time concept in the disciplines of sociology and anthropology, see: Werner Bergmann, *The Problem of Time in Sociology: An Overview of the Literature on the State of Theory and Research on the ‘Sociology of Time’, 1900-82*,1(1) Time and Society 81 (1992). For more on time as a social and historical concept, see: John Greville Agard Pocock, Politics, Language and Time: Essays on political thought and history 233-72 (1989); and the journal Time and Society, <http://journals.sagepub.com/home/tas>. [↑](#footnote-ref-69)
70. For writing on the critical social approach to time see: Barbara Adam, Timewatch: The Social Analysis of time 1995; on the time dimension and its social construction within the modern family experience, see: John R. Gillis, *Childhood and Family Time: a changing historical relationship*, *in* Children and Changing Family: Between Transformation and Negotiation 149 (An-Magritt Jensen and Lorna McKee eds., 2003) ; John R. Gillis, *Never Enough Time: Some Paradoxes of Modern Family time(s),* *in* Minding the Time in Family Experience: Emerging Perspectives and Issues 19 (Kerry J. Daly ed., 2001); as well as: Arlie Russell Hochschild, The Time Bind: When Work Becomes Home and Home Becomes Work (2001). [↑](#footnote-ref-70)
71. For time critique in feminist writing, see: Julia Kristeva, Women’s Time (trs. Alice Jardine and Harry Blake) 7(1) Sings 13 (1981); Frida J. Forman and Caoran Sowton eds., Taking Our Time: Feminist Perspectives on temporality 1989; Karen Davies, Women, Time and the Weaving of the Strands of Everyday Life 1990; Beth Anne Shelton, Women, Men and Time: Gender Differences in paid work, housework and leisure 1992. [↑](#footnote-ref-71)
72. Julia Kristeva, “Women’s Time”, *in* The Kristeva Reader(Toril Moi ed., 1986) 206–217. [↑](#footnote-ref-72)
73. Hughes et al., footnote 120 above, pp. 266 – 268. [↑](#footnote-ref-73)
74. Along with the gender aspects of the temporal dimension and their outcomes, the construction of the temporal dimension also influences the presence or exclusion of social groups. See: Johannes Fabian, Time and the Other: How Anthropology Makes its Object (1983). This book analyzes the employment of the temporal dimension in anthropological studies as a basis for the denial of “shared time,” or the establishment of “our time” and “their time” as a practice of social inclusion and exclusion. Social and scholarly assumptions regarding the uniform and general nature of the temporal dimension are used as a tool for excluding disenfranchised or minority groups (such as native populations) from the norm, or in other cases restricting them to narrow, normative time by erasing their uniqueness (ethnic groups, for instance). For an example of a study on a group of “others” as a result of the temporal dimension, see: Glenn Jordan, *Flight from modernity: time, the other and the discourse of primitivism*, 4 Time & Society 281 (1995). [↑](#footnote-ref-74)
75. For comparison, see Wendell’s discussion of the “modern pace / rhythm of life” as an additional environmental factor that amplifies the disability of those living with impairments in the public-professional sphere, see: Wendell, footnote 35 above, pp. 37 – 39. [↑](#footnote-ref-75)