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Configurations of atypical parenting activism in disability and chronicity

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Abstract *This article aims to reflect on the configurations of atypical parenting in the field of disability and chronicity. The atypical emic category composes with these fields. Associative symbolicities are explored with an ethnography in social media and interviews with activists. We indicate ongoing processes in the anticapacitist struggle that dialogue with agendas of Politics as Care. We conclude that "atypical activist parenting" operates with meanings and learnings of living and being familiar with disability/chronicity/rarity in proximity to a son/daughter, not being restricted to biographical ruptures.*

Key words *Activism, Gender, Health of persons with disabilities, Social discrimination*

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Introduction

Disability does not correspond to a disease; as a human characteristic, it acts as a social marker of difference, in functional diversities, in interaction with social, physical, and interactional barriers. Barriers based on asymmetries and oppressions, games of power and prestige, operators of the rituals of discrimination. We recognize disability as interdependence and Care as Politics[1-3].

In this article, disability operates as a field[4] in the dialogue with chronicity. We assume a demedicalized and affirmative disability, as well as chronicity not being synonymous with chronic disease, nor much less of its classificatory derivations. In the boundaries and borders of this interpretation, there is a heterogeneity and struggle with long-lasting structures, of which we highlight that of compulsory body normativity, where the requirement to standardize, correct, and normalize bodies and life routines is located.

The boundaries and borders of disability, as an analytical, political category and marker of difference, tension with the perspective of chronic illnesses[5-7], to reach the category of chronicity. Recognizing a body with other functionalities and expressions, complex and multiple needs, means negotiating with the diagnoses of chronic, rare, and complex health conditions, marked by extended temporality in coexistence. The chronicity category encompasses, but is not reduced or identified to the disease/health condition, nor its course and manifestation times, acute and/or chronic. It evokes temporality in bodily experience, in encounters, with what is interpreted, negotiated, intersubjectively. Chronicity means living with and managing life and the perennial, unevenly distributed care, as an expression and mediating characteristic of living life and its costs. Chronicity and Disability are categories with borders in permanent friction for those living with a rare and complex health condition. In this discussion, atypical parenting is configured as: fathers, mothers, sons, and daughters, in spheres where often specialized knowledge and health care circulate, as well as schooling processes. We assume atypical as the emic category of the studied field, along with other expressions, such as neurodiverse and/or neurodivergent, in profiles, posts, and public debates. The use of the expression atypical refuses the dichotomy normality/abnormality.

Atypical children and adolescents, in disability, chronicity, and rarity, have their bodies very mobilized, investigated, and enunciated by numerous knowledge and disciplines, developing an embodied/incorporated knowledge[8-13]. The *status* of the child and adolescent as subjects – whose rights refer to the responsibility of reference adults, or in the absence of these, the State – demarcates the category of "protection". This category of "protection" evokes cosmologies that can reduce children and adolescents with disabilities to beings "absent from talking about what is going on with them". Combining this imaginary with the differences that disability and chronicity evoke, we have even greater possibility of disregarding them as subjects who can express their knowledge and desires, in an active process of invisibilization.

In atypical parenting, the traditional and expected roles of fathers and mothers[14] gain other meanings – of defending their sons/daughters as subjects who must have rights, of fighting against their dehumanization, and for inclusion –, qualifying an activism. Deslandes[15] conceptualizes activism, connecting it to the digital environment and problematizing its political reach. We understand activism – not taking social media as an object, but a place where we investigate the guidelines of atypical parenting – in the connection with Care as Politics: expressing hours of study, dedication, and work, as well as struggles for affirmative action, social inclusion, access to care goods, *advocacy* against the State and its agents (teachers, health professionals, public managers, legislators). In Test *et al.*[16], self-*advocacy* implies knowledge of self and rights, communication and leadership, and empowerment. Speaking or acting for oneself, making decisions, and assuming responsibilities reside in this concept. In the studies by Ribeiro *et al.*[14] on parenting review, Deslandes[15] on digital activism, and Taste *et al.*[16] on *self-advocacy*, we recognize dialogues to assume that atypical parenting activism is not reduced to any of these dimensions, but is configured in a contemporary phenomenon as associative symbolicities[17]. The associative symbolicities contemplate the moral foundations that drive people to be together in the struggles for objective and subjective rights, circulating gifts and counter-gifts, symbols of association and solidarity. We recognize these associative symbolicities in Care as Politics, in the *advocacy* of atypical parenting.

The activism and struggle "for" and "by" sons/daughters can combine the creation of civil organizations with CNPJ (National Registry of Legal Entities) and public presentation in the digital universe. It is with this public parenting that we negotiate here. We resort to the feminist perspective of Ethics of Care and Disability[1,2] and the Feminist Anthropology of Childhood[17-22] to interpret the research collection. The marginality of the Feminist Anthropology of Childhood[23] contrasts with the urgency of recognizing children in societies, especially those with disabilities, who are more vulnerable to violence[24]. In this article, we enunciate possible configurations of atypical parenting, in the field of disability and chronicity, in the light of the perspective of associative symbolicities.

We question: How are agendas and guidelines of social inclusion updated by atypical parenting activists, and articulated with differences of gender, class, territory, and generation, translating activism in the configurations of associative symbolicities?

Care as Politics and the Feminist Anthropology of Childhood

We activate feminism in the frameworks of disability as interdependence, ethics and politics of care, a conceptual, transversal, and constitutive attribute of human existence[1,2]. Kittay[1,2] discusses independence as a neoliberal myth, which reduces, dehumanizes, and discredits dependent people. Dependence gains a moral or psychological stigma – as pathological and a source of discredit – in the economic aspects and in social interactions. This diluted moral stigma in society, and located in the State, was the target of the "idea of independent living" of the first generation of disability theorists and activists in this field[2]. They sought to assume independence not as self-sufficiency, but as self-determination.

For the author, disabilities affirmatively rescue Care and dependence on personal and political networks, requiring more or less of these networks according to the diverse functional expressions of disability. Discrediting the myth of independence, to manage dependence. According to Kittay[1,2], by assuming our dependencies, we select and optimize: opportunities, efforts, shortcomings, and we fight for political rights before the State. Kittay[1] does not oppose an ethics of Care to an ethics of Justice. The author posits a theory of justice linked to and promoting an ethics of care, distinct from theories of canonical justice, with necessary principles to recognize our inevitable dependence and inextricable interdependence in social life.

In the field of atypical parenting, where care for children and adolescents with disabilities is located, we seek arguments for a denaturalization and deprivatization of childhood[17-21], in the discussion of motherhood, childhood, and feminism. Even starting from a generic childhood, the articulations between gender and age/generation are strategic in these feminist debates, summoning motherhood in different historical and cultural contexts, institutions, and social circumstances. Gender and generation are starting markers, incorporating race as a marker of oppression by the contributions of the Black Feminist Wave. If for white women the struggle was to free women to go beyond motherhood, for Black women the space of home and motherhood are configured spaces of struggle and affirmation, in the care of their sons and daughters, as owners of their space, unsubmissive to white supremacy and oppressive relations[25].

The intersections between race, gender, disability, class, generation, and territory are fundamental in the expressions of the activism of "atypical" mothers and fathers and in the anti-discrimination struggles for the non-dehumanization of their sons and daughters.

The methodological craft

We assume digital social media as research universes, where we situate atypical parenting activism. By the immersion in Facebook and Instagram pages, we reached several profiles where the agendas of disability and affirmation of people with rare diseases were placed. We selected those autonomously named atypical parenthood, with frequent activities – encompassing profiles of fathers and mothers – and guidelines for diversity and for inclusion of race, gender, and rights of children and adolescents with disabilities and rare diseases. Our previous research on the associativism and rights of people with rare diseases, and on mothers with children with congenital Zika virus syndrome, made it possible to include three women with histories of associativism and activism in social networks. We invited fifteen activists by private message in their profiles, and eight women and three men agreed to take part with interviews by image and voice applications. These interviews gathered the observation and frequency in the digital pages, *lives*, *posts*, invited meetings that we attended between the years 2019 and 2021.

The knowledge of experience as a moral authority circulates and disputes, negotiates and consumes scientific evidence, with technical authorities, in a place of recognition, dissemination of ideas, organization of vocabularies for political struggles for social inclusion. We evoke social inclusion, affirming diversity, with Geertz[26], and we follow with ethnography as a methodology. Diversity, announced and defended in the collection studied, appears as functional diversity or related to the body with disability, in the marks of chronicity and rarity, and in atypical parenting. We intentionally chose profiles of fathers and mothers of children with disabilities and rare and complex health conditions, with affirmative, inclusive political agendas critical of conservatism.

Ethnography, in times of pandemic, with digital sources and techniques, brings us closer to various points of view: on child and disability, motherhood and fatherhood transversalized by the experience with disability and chronicity, self-named atypical. We value the interpretation and symbols, vocabularies and notions, which face and translate criticism of the long-term structures of a racist, adult-centric, and capacitist patriarchy. Capacitism is equivalent, in the grammatical forms of discrimination, to prejudice against people with disabilities, understanding them in the frameworks of body normativity. Geertz[26] defends the cultural diversity of the circumscribed ethnic or national groups, which universal systems of thought oppress and seek to make invisible.

The interpretation supported by the theoretical-critical reflexivity of the approved research collection – CAAE 29962720.1.0000.5269 – followed a craft of synthesis of ideas and questions with Care as Politics and Interdependence, and the Feminist Anthropology of Childhood. We submitted the collections of observations and interviews to a dense reading, with theoretical notes, identification of emic categories, questions posed to the field of experiences, to understand atypical parenting as a configuration of activism for the rights of children and adolescents with disabilities and chronicity situations. Without cutouts of speeches, *posts*, interviews, we operate with the authorial reflexivity of those who write here, considering the provisional nature and speed of this field, in a contemporary scenario of digitization of life.

Interpretative synthesis: dialog between collection and authors

Regarding the interviewees, four women direct/coordinate organizations with CNPJ with or without physical headquarters: two with rare diseases, one with the field of disability, and another linked to the field of support for children and adolescents with microcephaly due to Zika Virus or other microcephaly situations linked to disability. The other four women, between the ages of thirty and forty, assume an anti-racist and anticapacitist critical feminist agenda, in a self-reflexive process critical to the idea of atypical parenting, as a place of abandonment, suffering, correction, guilt, and restriction. Of the eight women participating in the survey, one discusses male abandonment, but stating that it was she who sent the father of the children away; six others are married to the fathers of their children; and one is divorced from the father, but lives with shared custody of the teenage daughter. Paternal abandonment was not a tonic in this collection. Concerning the three men we interviewed and whose social media we attended, only one is divorced from the mother of their children, and actively shares custody of these, including care for the child living with a rare disease. The other two men became parents for the second time, to babies who are not atypical. We emphasize that the men interviewed are not partners or married to the women we interviewed.

For three interviewees from institutionalized organizations – two older, related to the activism of rare diseases, and the third to the activism of the Zika epidemic –, there is a symbolism of the struggle in favor of the identity of the "*rare, unknown, disease of the specialist*", and, for the third, most recent, of a struggle to denounce and claim responsibility from a State absent in the Zika epidemic. Such symbols anchor meanings of groupality, collective struggle, support, and mutual aid in an institutionalized way, with physical headquarters and a CNPJ. In these symbols, there is a link to the "pre-occupy" with the other, in a large family culture, where the circulation of children and care is assumed without anyone needing to oblige them. For the third interviewee of an organization with CNPJ, the focus is disability and local support actions.

There is an expectation in this generational group that helping, organizing, generating solidarity "*is part, constitutes this*". For two of them – who are of the generation with or close to 60 years old – the networks with the church favor the awareness of diversity and inequality, gather information and guidance, report violence and abuse, as a solidarity woven in daily life, in proximity and informality. This component includes stories with trajectories of union organization, struggles for and at work. The limits of an institutionality that the internet does not offer, due to the absence of physical presence, coexists with the recognition that this space is configured as a place of interest for banal, common subjects, which gather *likes*, followers, and thousands of views. Therefore, they can be used for punctual actions of celebration of dates, events, disclosure, and fights. The criticism made assumes that a collective face-to-face mobilization is necessary for the "*struggles of/for diseases*". There is a strong link with the reference services unfolding in networks of networks: a reference mediator of the specialist doctor, to become herself "an expert" in mediation, administrate agendas and reference and guidance networks, in attributes that do not reduce them either to the maternity achieved in contact with a knowledge that no one had nor to the profession of managing and assisting medical demands. An identity at the borders, strongly linked to Care. This word is full of meanings in this associative field in its symbolicities: qualified reference, support, solidarity, recognition, knowledge acquired by experience.

The arena of disputes becomes complex, enabling or not the emergence of alliances between atypical maternity and paternity, and other spaces where associativism is configured. Martins[17] articulates, from the perspective of social bonds and gift between strangers[27], macro and micro social processes, in the associativism of the constitution of alliances and solidarities. These may or may not refer to the more permanent associative logics, triggers of the public sphere as democratic and participatory *locus*, overcoming sectorialized identities. This analysis supports us in the discussion between seeing oneself in the associativism nucleated in militancy by the identity of the disease and/or disability, or overflowing and reaching other affirmative agendas.

For another activist over 50 years old, with organization with CNPJ and headquarters, to realize that the disability of her Black child was due to obstetric violence, a caesarean section done late, delimits her antiracist struggle. In this trajectory, the interviewee reconstructs herself in paths in special education, in the demands of caring for this child. There is a symbolism in "graduating" by and in experience, but without giving up a dialogue with the institutions that "graduate", and that allow them to present themselves publicly not only by motherhood, but by profession[28].

Children with disabilities, black, poor, peripheral, and "atypical" are at a greater disadvantage and more exposed to segregation. The symbolic function of associating creates circuits of orientations, references, and affective and moral supports. It refers to the struggle for asserting oneself in the face of social belonging interpreted through the lens of discrimination, oppression, and exclusion. Obstetric violence is not random: it has race/color, class, and territory. Hence the term is updated as "*obstetric racism*" by our interviewee.

Care is intertwined with the "experience of marginalization"[29](p.15) for certain people according to their marks of belonging referred to social inequalities. These experiences, subjected to critical reflexivity, to the need of seeking references, their peers, and collectivized places, support their "perspectives"[30](p.137) in their look and voice over the world. Molinier and Paperman[31] defend the decompartmentalization of care – removing it from a "psychologized" sentimental essence – to involve it in a theory of "point of view". This is an attempt to take the point of view against the invisibility of important aspects that the theory of care can illuminate in the production of knowledge, in the links between singular lives and broad social processes. In the trajectory of one of the interviewees, with a late schooling process and poverty, having had a teacher who cared for her, including taking her to her home to offer her care, appears in the way she is organized to support other women today. In turn, a man plunging into feelings of ambivalence, shame, fear, sadness at the birth of his atypical daughter made him write a children's book, provoke public conversations with other men and women in a similar situations, and gather in a group of atypical fatherhood.

The intersection between atypical maternity and paternity and the generation marker allowed us to analyze places where the agendas, ideas, and values for influence and change circulate. In women over 50 years old, it is in the face-to-face space of organizations, groups, house meetings, associations of residents, churches and waiting rooms of outpatient clinics, and hospitalizations in the wards of public hospitals, that an associative and struggle capital gains contours and configurations. In those between thirty and forty years, digital social media represent a capital of mobilized youth and with investments that articulate physical distance and proximity of agendas, linked to the recognition of learning and struggles for inclusion, with an intersectional basis: in the field of inclusion; for women's rights; in antiracist, anticapacitist, and solidarity economy struggles. These interviewed activists have higher education and work relationships that in the pandemic enabled remote work, in the areas of journalism, public service, communication, and education, with many burdens for care at home and with therapies for sons and daughters.

Frequently, these profiles and *posts* are challenged by other agents who, with conservative perspectives, "attack" ideas and threaten people. In a transit between exposure and risk, struggle and affirmation, some interviews clearly stated that the meaning of network – when asked for actions on the internet and in the plan of care in the home, school, and street environment – was much less of help and more of protection. And in this case, protection gains the meaning of defending oneself not only from capacitist discourses, but from racial hatred. This difference between "*support network and protection network*" came from a Black woman, from the periphery, with a strong family network, and diagnosed with disability in adulthood. We enunciate how the conservative environment rivals, strains, and goes against the transforming environment of the agendas of rights to difference, which digital environments potentiate. We resorted to Zelinzer[32] and hooks[25], the first questioning the traps of binarism that conservatism feeds, building manicheisms to sustain its logics and expand. In turn, in hooks[21] we reassess the meaning of resistance of the home, of motherhood, of the street, for Black women. By guiding atypical motherhood and paternity, three of the Black women interviewed defend not only an anticapacitist struggle – to overthrow the ideals of normality, prejudices, and barriers – but an antiracist one. This antiracist struggle denounces the erasure of Black children and adolescents with Down Syndrome from the public scene. By a shared profile – of a father of a Black boy with Down Syndrome – we read Santoro[33] and arrived at Yang *et al.*[34], whose data indicate that Black people with Down Syndrome live less than white people with the same condition. Another profile made us arrive at Fang *et al.*[24], who highlight the greater vulnerability of children with disabilities to violence. These profiles circulate evidence from research that faces opinions that obscure rights, favoring commitments to inclusion and diversity. Moreover, they value the atypical child and adolescent at the center of the care scene and the schooling processes, vocalization of desires, communication, whether alternative or not. Thome[18], Alanen[19], and Oakley[35] criticize "adultism" or adultcentrism, in the disregard of the child, as a way to face hierarchies of gender, class, and race.

The circulation of symbols of struggles, articulated to the agendas of atypical parenting, disability, chronicity, and rarity – at the intersections between common knowledge, scientific knowledge, activism for rights – is an important key to sustain the agenda of social inclusion. Why do we highlight this agenda relating to what we have been discussing so far? Because inclusion operates with its double negative, exclusion, which has as its background structural processes and grand narratives that support oppression, discrimination, and justify historical violence against certain groups: women, Black people, children, the elderly, people with disabilities, and Indigenous peoples.

Here returns the analytical key of disability as field[4]. We do this because the many disqualifications and discriminations that operate against people with disabilities are faced with statements of atypical parenting, either in the associative basis, or in digital activism, or even in the historical social movement. In this field, academic knowledge is produced, and knowledge circulates, disputing disability, configuring it as a political and non-medicalized category. Refusing sickness or seeing one's son or daughter as sick means straining with the body-normative, corrective, classificatory, statements of biomedical logic.

In these arenas that organize themselves and are organizers of public interests and discourses, it is worth asking how the symbolism of chronicity/rarity/disability/atypicity can connect symbols of expansion of identifications and solidarity. The provisional response comes from assuming as legitimate the corporeity with disability/chronicity/rarity/atypicity. Claiming a place of authority over experience, in the affirmation of rights to Care as Politics and Justice of Difference[2], recognizing oneself black, white, woman, man, child, teenager, old, young, worker, etc. In this direction, it is urgent to evoke the concept of intersectionality[34] and include the quality of the "atypical" emic category as an identity marker that can coexist with and fold over others. One must affirm qualities that communicate, leading to a multi-reference, by overcoming sectoral segmentations, and articulate common identity traits[35], relating three dimensions: *otherness*, *recognition*, and *belonging*. Such dimensions contribute to the reflection on social interactions, in the construction of associative symbolicities.

Regarding intersectionality[36], social markers of difference are not equal to metric variables and classifications. Reference systems that precede and hierarchize us correspond to social markers – gender, race, class, territory, disability, generation. Intersected, they will increase inequalities.

Investigating atypical parenting means reconceptualizing care as interdependence[1,2], and taking it as "perspective" and "point of view", intersectionally. The Ethics of Care as Politics dialogues with the world of work and with gender inequalities and moralities. Interpersonality resides in care relationships, with multiple protagonists (individuals, groups, and institutions), hierarchies in their location as work in the different stages of life, and in their responsibilities[35]. Interdependence and vulnerability, virtuous symbols of culture, human marks, take back difference as an affirmative basis.

In the generational or territorial perspective, for women of the generation between 50 and 60 years old, from the peripheries, where chronicity/rarity/disability build meanings of associativism, face-to-face relationships in formal organizations predominate. The female group of the "*coffee and cake at home*" also prevails, as the basis of their first associative nuclei, in the care of atypical children who were born, and whose mothers, fathers, and even health professionals needed guidance. In a playful form of socialization and sociability, in cooperation and collaboration, in interaction through unpretentious conversation, which articulates playfulness and elaborates conflict[37].

For one of the interviewees – whose activism is linked to the Zika Virus epidemic, and its repercussions on her daughter's microcephaly –, meeting with other women, whose sons and daughters live with this condition and others of chronicity and disability, denounces the State as debtor and cause of this condition, congenital zika syndrome, as extraordinary. In this hybrid experience of the interviewee, it is urgent to have a headquarters to gather, offer, receive, and also be in digital social media sharing knowledge related to care, producing articles, attending academic environments and public hearings. By founding organizations, the generation of women over the age of 50, or those organized from the Zika epidemic, in their 30s and 40s, seek peers and shared symbols in common – to be rare, to live with a body in a society that limits them, to learn from technical discourse and to master it to be recognized, to seek rights and supports[38].

Atypical parenting activism in networks reinterprets the experience of care as a work of activism. We follow Herzlich[39], valuing – without equivalence to biographical rupture with multiple losses[40] – the overflow of the private experience of the disease to the universe of public visibility, articulating the civic, political, and associative character, in the search for peers and bonds.

With Tilly[41], we activate large and small narratives, in the relationship between structures of large and small duration, in the set of networks and associative symbolicities[23]. This digression operates in a sociological exercise of understanding social changes.

We bet that atypical parenting – in the experiences of discrimination, coping and reconstruction of communication processes, negotiation with the health and education of their children – reach criticism of the great social structures of the political field[4], by denouncing other oppressions: capitalist, patriarchal, gender, racial, medicalization of life. The medicalization of life operates on emotions, reducing the resignification of experiences of suffering and corporeality, distancing them from sociocultural anchorages.

Based on Tilly[41], we recognize the difference between objects on which he focused – social movements and the organization of national States – and what this article discusses: the public field of atypical parenting activism. We do not see in this object equivalences to the traditional definitions of social movements. Nevertheless, we observe network configurations of associative symbolicities[17], joined to critical struggles with powerful reflexivity processes, tensioned with conservative and reactionary movements and networks of segregation in education, concordant with a moment of the Brazilian State where this is defended.

Concerning parenting models, there is a hegemonic paternity / masculinity tension and expectations that naturalize the paternal abandonment of sons and daughters marked by disability / chronicity / atypicity. When following digital pages, other ways of being, existing, and parenting appear. In arrangements of separated parents, abandonment does not occur, but shared care, not interpreted as help, favor, or concession. There are men who trigger memories of care as children, and who evoke other possible utterances. In an interview, the lament of a father was how much he would have to reinvent other ways of living fatherhood, distinct from a corporeality of his daughter, where walking, talking, being received when arriving from work or school would not occur as it was with him as a son. For men, more than for the women we followed, there is a process of returning to references, views, and learning as children, triggering pain, fears, mental health processes that challenge the axis sadness/joy/personal fulfillment.

A critical reflexivity triggers the sensitivity of men to – with some pain – reinvent themselves, deconstructing capacitist discourses. For the three men interviewed, the structure most placed in crisis was that of the relationship between the genders, with the models of masculinity, parenting, and paternity. For one of them, whose experience triggers his link to the collectives of marginal poetry, another structure strongly criticized is the confinement of discussions, meetings, groups to the space of specialized hospitals. His experience refers to the elaborations of caring for a child with a rare syndrome. He strongly criticizes what we call a "hospitalization of organizations," linked to the structure of medicalization of care. According to them, when a child or adolescent with disabilities occupy a public space, a political act is materialized.

Final considerations

Atypical parenting activism affirms the legitimacy and the right to care as politics for their sons and daughters. With other vocabularies and ways of being legitimate in the world, they influence the agendas of anticapacitism, antiracism, for rights through accessibility, inclusion, and diversity. They face conservative plans of ideas about childhood, adolescence, parenting of sons and daughters with life situations marked by chronicity/rarity/disabilities. There is thus a friction/tension with gender, race, class, and territory inequalities. Family and care arrangements within and outside the family, and the legitimate place of existence of their sons, daughters, and themselves, represents a political movement.

"Atypical activist parenting" reconfigures meanings, symbols, and learnings of living and being familiar with disability/chronicity/rarity in caring for a son/daughter, overcoming biographical ruptures and losses. Acquisitions come from a critical reflexivity on personal experience and one's place in the world, to ensure care, family organization, and rights.

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References

1. Kittay EF. *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge; 1999.
2. Kittay EF. *Dependency in Keywords in Disability Studies*. New York: NYU Press; 2015.
3. Gesser M, Fietz H. Ethics of Care and the Experience of Disability: An Interview with Eva Feder Kittay. *Rev Estud Fem* 2021; 29(2):e64987.
4. Bourdieu P. O campo político. *Rev Bras Cien Pol* 2011; 5:193-216.
5. Barsiglini R. Adoecimentos crônicos, condições crônicas, sofrimentos e fragilidades sociais: algumas reflexões. In: Canesqui AM, organizador. *Adoecimentos e sofrimentos de longa duração*. São Paulo: Hucitec; 2013.
6. Moreira MCN. E quando a doença crônica é das crianças e adolescentes? In: Castellanos MEP, Trad LAB, Jorge MSB, Leitão IMTA. *Cronicidade: experiência de adoecimento e cuidado sob a ótica das ciências sociais*. Fortaleza: Ed. UECE; 2015.
7. Wendell S. Unhealthy Disabled: Treating Chronic Illnesses as Disabilities. *Hypatia* 2001; 16(4):17-33.
8. Wheeler V. Lauren aged 10 years: So you are thinking of having a gastrostomy? *J Child Health Care* 2003; 7(2):85-88.
9. Coughlan C, Liddell B, Watson M, Blair M. Rethinking complex needs with patient and carer perspectives. *Lancet Child Adolesc Health* 2020; 4(10):719-720.
10. Swain K. Spare a little time. *Lancet Child Adolesc Health* 2021; 5(2):101-102.
11. Castro BSM, Moreira MCN, Szapiro AM. Crianças e Adolescentes com Condições Crônicas Falam Sobre Saúde. *Rev Polis Psique* 2018; 7(3):116-135.
12. Goodley D, Runswick-Cole K, Liddiard K. The DisHuman child. *Discourse* 2016; 37(5):770-784.
13. Moreira MCN, Macedo AD. O protagonismo da criança no cenário hospitalar. *Cien Saude Colet* 2009; 14(2):645-652.
14. Ribeiro CR, Gomes R, Moreira MCN. A paternidade e a parentalidade como questões de saúde frente aos rearranjos de gênero. *Cien Saude Colet* 2015; 20(11):3589-3598.
15. Deslandes S. O ativismo digital e sua contribuição para a descentralização política. *Cien Saude Colet* 2018; 23(10):3133-3136.
16. Test DW, Fowler CH, Wood WM, Brewer DM, Eddy S. A conceptual framework of self-advocacy for students with disabilities. *Remedial Spec Educ* 2005; 26(1):43-54.
17. Martins PH. O dom como fundamento de uma cultura democrática e associativa. In: Portugal S, Martins PH, organizadores. *Cidadania, políticas públicas e redes sociais*. Coimbra: Imprensa da Universidade de Coimbra; 2011. p. 13-27.
18. Thome B. Re-visioning Women and Social Change: Where are the Children? *Gender Soc* 1987; 1(1):85-109.
19. Helleiner J. Toward a Feminist Anthropology of Childhood. *Atlantis* 1999; 24(1):27-38.
20. Alanen L. Gender and Generation: Feminism and the 'Child Question'. In: Jens Qvortrup J, Bardy M, Sgritta G, Wintersberger H, editores. *Childhood Matters*. Aldershot: Avebury; 1994. p. 27-42.
21. Alanen L. Estudos feministas/estudos da infância: paralelos, ligações e perspectivas. In: Castro LR, organizador. *Crianças e jovens na construção da cultura*. Rio de Janeiro: Ed. Nau, FAPERJ; 2001. p. 69-92.
22. Alanen L. Teoria do bem-estar das crianças. *Cad Pesqu* 2010; 40(141):751-775.
23. Caputo V. Anthropology's Silent 'Others': A Consideration of Some Conceptual and Methodological Issues for the Study of Youth and Children's Cultures. In: Amit-Talai V, Wulff H, editors. *Youth Cultures: A Cross Cultural Perspective*. London: Routledge; 1995. p. 19-41.
24. Fang Z, Cerna-Turoff I, Zhang C, Lu M, Lachman J, Barlow J. Global estimates of violence Against children with disabilities: an updated systematic review and meta-analysis. *Lancet Child Adolesc Health* 2022; 6(5):313-323.
25. hooks b. Constituir um lar: espaço de resistência. In: hooks b. *Anseios: raça, gêneros e políticas culturais*. São Paulo: Editora Elefante; 2009.
26. Geertz C. *Horizontes Antropológicos*.1999; 5(10):13-34.
27. Mauss M. Ensaio sobre a dádiva. In: Mauss M. *Sociologia e antropologia*. São Paulo: Cosac & Naif; 2003.
28. Moreira MCN. Trajetórias e experiências morais de adoecimento raro e crônico em biografias. *Cien Saude Colet* 2019; 24(10):3651-3661.
29. Williams M. *Voice, trust, and memory: marginalized groups and the failings of liberal representation*. Princeton: Princeton University Press; 1998.
30. Young IM. *Inclusion and democracy*. Oxford: Oxford University; 2000.
31. Molinier P, Paperman P. Descompartimentar a noção de cuidado? *Rev Bras Cien Pol* 2015; 18:43-57.
32. Zelinzer VA. Dualidades Perigosas. *Mana* 2009; 15(1):237-256.
33. Santoro S. Uncovering Racial Disparities in Down Syndrome [Internet]. 2016 [cited 13 mar 2021]. Available from: https://pediatricsnationwide.org/2016/05/19/uncovering-racial-disparities-in-down-syndrome/.
34. Yang Q, Rasmussen AS, Friedman JM. Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population-based study. *Lancet* 2002; 359(9311):1019-1025.
35. Oakley A. Women and Children First and Last: Parallels and Differences Between Children's and Women's Studies. In: Mayall B, editor. *Children's Childhoods: Observed and Experienced*. London: Falmer Press; 1994. p. 13-32.
36. Piscitelli A. Interseccionalidades, categorias de articulação e experiências de migrantes brasileiras. *Soc Cultura* 2008; 11(2):263-274.
37. Simmel G. *Questões Fundamentais de Sociologia*. Rio de Janeiro: Zahar; 2006.
38. Scott P. Cuidados, mobilidade e poder num contexto de epidemia. *Mana* 2020; 26:e263207.

39. Herzlich C. Saúde e doença no início do século XXI: entre a experiência privada e a esfera pública. *Physis* 2004; 14(2):383-394.
40. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982; 4(2):167-182.
41. Tilly C. *Big Structures, Large Processes, Huge Comparisons*. New York: Russell Sage Foundation; 1984.

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