

**SURVIVAL OF THE MISFITS: DEPENDENCY CARE AS A SITE FOR
POLITICAL REPRESENTATION**

by

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ABSTRACT

From physicians advising families to pull the plug on the to-be-disabled, to the eugenics movement and sterilization laws, at the core of threats to the existence of dependents with severe disability are narratives of tragedy and *misfittedness*. Through this horizon, the embodiment of difference is ostracised as deviancy or deficiency and dependents living with severe disability are least recognizable as political subjects due to their structural positioning--casting relations of care to the margins of public accountability. What increases the risk of death, violence or injury is not the dependencies or corporeal embodiment of individuals with severe disability, but rather the lack of institutional support for relations of care--their primary means to sustenance. The multi-dimensional practice of care, as it arises from dependency and corporeal vulnerability, is a political resource through which dependents with severe disability can exercise a greater degree of authorship and self-definition in the democratic claims-making process. Central to this task is mapping the alignment between the values of attentiveness and responsiveness, at the heart of the ethics of care, and what democratic representation draws its legitimacy from: proximity and attention to the particularity of the represented. The shared perspective between dependents and dependency workers, looking out from a dependency relation, when mobilized in the process of representation, paves way for the empowerment of the dependent because it increases not only his self-esteem as an individual, but also, the performance of institutions of care--shielding dependents from the differential distribution of precarity. The process of representation, as exercised through the activity of care, must be as fluid as the move from wheelchair, to walker, to cane, to his one's own legs—whatever the shifts in capacities may be for the dependent, the dependency worker adjusts her care through attentiveness. This requires reconciling the politics of presence with the physical (the corporeal situation of the political subject): designing institutions in a way maintains an ever-present, ear to the ground, process of representation between the representative and the represented, which is also, fine-tuned to the particularity of the individual's structural positioning, the changing human body, perspectives etc.

PREFACE

This thesis is original, unpublished, independent work by the author, S. Munawar.

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I wrote this for my father who taught me what it means to be human, what it means to really be there for someone, for dependency workers like my mother who constantly put the needs of others before their own even if it puts their own life at risk, for young carers like my baby sister who wake up to administer feed through g-tubes in the night and go to high school in the morning, and for the families of individuals with severe physical or neurological disability who are on the frontlines of an all too human, and all too real struggle for survival and recognition. The personal is all too political, and my research is indebted to the inspiration I've found in the stories of struggle, resilience and raw human connection in the last few years moving from one care facility to the next with my father.

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Finally, I'd like to thank my mother whose strength, spirit and smile inspire me to wake up in the morning and continue to labour for my existence, and for the capital T truth, not for myself, not for academia, but for the sake of the human condition.

DEDICATION

For Abu Jaan, Ami Jaan, Mishaal, Ammar, Alina, Nanoo and Uzma Khala.

SECTION I: Introduction

Propelled by a pair of arms, a body bound to a mobile bed moves its way through a conspicuously spacious convenience store in search of cigarettes.

Another body declared medically comatose is transported on a stretcher by two nurses to the barbershop for his monthly haircut. Two feet followed by wheels, and an eye-patch race to the gymnasium for her 2 o'clock physiotherapy. And, my father with trach still fresh in his throat, is transported by the physiotherapists and the Hoyer lift from the bed into the chair, like a crane transferring concrete, for an hour daily, in hopes of walking again. My family's first day at the continuing care facility was written through the lens of society as a fall from grace of a self-made man--a great capitalist tragedy. From the outside looking in, the place seemed like an island for misfits: somewhere people had to go when an unfortunate series of events made them unfit for the outside world.

The space was full of bodies marked by abnormalities functioning in alternative ways beyond my imagination. Here, there were wider hallways, railings for support, pens with thicker grips, lifts and swings, and the temporarily able-bodied adjusted their flow to accommodate the speeds, rhythms and movements of the patients. But what about the world outside? Where people stare one second too long at marked bodies; where sidewalks are not wide enough to fit moving beds; where the slightest speech or linguistic deviancy invokes confusion and hesitancy

to engage? At the center of this capsular world, I remember there was a fish tank. Were these individuals like the fish in the water, who could only exist and function within the context of the care facility? Or were we all like the fish because, like them, we move in and through our relation to our bodies, each other and our environments?

After a few years of moving with my father from one care facility to the next, we learned that it was not him or other individuals with severe physical or neurological disability located in care facilities that was the problem. His reality was a brute reminder of shared human vulnerability and the universal need *to be cared for*¹, the moral obligation *to care for* and the political commitment *to care with*. We are born relying on others for sustenance and with the churning of time, be it through growing old or a 3-second accident or bout of illness, we will enter into a relation of dependency once again. However, if the frailty of the human body cuts across race, gender, class etc, then why were the lifestyles contained in this capsular world so removed from my understanding of what it meant to be human? And as a political theorist, how am I going to reconcile my father's reality with the embodiment of citizenship in a way that not only recognizes his dependence on relations of care for self-determination but also, unravels the association between vulnerability and powerlessness. Through this personal

¹ Gilligan, Carol. *In a Different Voice Psychological Theory and Women's Development*. N.p.: Harvard University Press, 1993. Print. p.98

vignette², I will illustrate how the multi-dimensional practice of care, and the relational affinities specific to it, challenge us to expand the horizons of political representation to pave space for more authorship³ by dependents for dependents⁴ in the claims-making process.

Though relations of dependence entail an inequality of power, such an asymmetry need not entail a relation of domination. In *Caring Democracy*, Joan Tronto argues that care should be a “large-scale democratic project” because “democratic caring is not only better because it is more democratic, it is better because it provides better care”⁵. Also, the greater sharing of responsibilities for care, on a public level, the less people have to fear and the “more easily they can trust others”⁶; and so, grounding democratic theory in an ethics of care and an ethics of care in democratic theory, through fostering positions of trust, the world will become “more open, more free, more equal and more just”⁷. The ethics of care, in particular, flows from the work of Carol Gilligan whose arguments compose the foundations of this paper. Animating the frameworks of Held, Butler, Nedelsky, Kittay and Tronto is the spectre of feminism. The themes of relational

²After a double stroke, anoxic brain injury and cardiac arrest, and 2 years of relying on institutionalized care, my father is now at home, in a relation of care with our family and his care team as our family learns to adapt to life post-stroke.

³ In this paper I choose to use the word authorship, over voice, to argue that care is a medium through which individuals can project themselves into the world. By authorship I am referring to the Arendtian notion of action through which agents reveal their *whoness* and the importance of telling your own story through your interactions with men qua men. Arendt, Hannah. *The Human Condition*. N.p.: The University of Chicago Press, 1998. Print. p.184-186

⁴ With this I echo the motto “Nothing about Us without Us” minted by the Disabled Peoples Organizations, referenced by the UN in regards to the International Day of Disabled Persons. This principle maintains that efforts at achieving “full participation and equalization of opportunities” for persons with disability must be in collaboration with or by persons with disabilities (2004).

⁵ Tronto p.18

⁶ Tronto p.146

⁷ Ibid.

persons, "medicalization of the body, the politics of appearance, the privilege of normalcy", connection-based self-determination, care and the public-private division of labour are inherited from the canon of Western feminist scholarship⁸.

Relations of care and the lived experience of dependents can be used as a mirror to evaluate to what extent a liberal democratic society offers the "institutional conditions necessary for enabling self-development and self-determination" of its most vulnerable members⁹. The primary purpose of a care-based model of representation is to increase the recognisability of dependents by activating the inter-group affinities between them and dependency workers to mobilize the latter as advocates for better care and support for relations of care in the public sphere. This can only be accomplished through second-order tasks which take place in daily interactions between the dependency worker and the dependent, especially in the context of institutionalized care, through which the dependent actualizes his self-determination. And these second order tasks are not only directly linked to institutional performance, and the health of a democracy but also, invite experimentation with new forms of responsiveness in the representation process--paving way for creativity and democratic innovation. By reconciling the politics of presence with the physical, the corporeal situation of the political subject, through decentralization of modes and sites of representation and attention

⁸ ⁸ Garland-Thomson, Rosemary. "Integrating Disability, Transforming Feminist Theory." *NWSA Journal* 14.3 (2002): 1-32. Print. p.4

⁹ Young "Inclusion" p.34

to particularity through proximity, we can not only facilitate the empowered inclusion of dependents, but also, invite investigation into the ontology of political representation itself and the demands we can make of it for the sake of democracy.

SECTION II: Judging a Fish by its Ability to Climb a Tree

Buried in the rhetoric of legitimacy in discourses on democratic inclusion is the rudimentary union between inclusion and survival, as well as exclusion and extinction. Individuals or minority groups on the margins of visibility have limited access to protection from injustice because the forms of oppression which differentially expose them to risks are also at the margins of public accountability. And so, the cries for help by the most vulnerable members of society are either contained in static echo chambers or filed as white noise, irrelevant to mainstream concerns. From physicians advising families to pull the plug on the to-be-disabled, to the eugenics movement and sterilization laws¹⁰, at the core of these threats to the existence of dependents with severe disability are narratives of tragedy and stereotypes of maladjustment¹¹. Both stem from exclusionary systems of representation, negative images of disability and homogenous norms of personhood embedded in hegemonic discourse and the liberal¹² embodiment of citizenship.

¹⁰Pfeiffer, David Pfeiffer. "Eugenics and Disability Discrimination." *Disability & Society* 9.4 (2007): 481-99. Web. 14 July 2014.p.489

¹¹ Pfeiffer p.488

¹²It is important to note here that it is not the case that the dependent is unfit, flawed, or incomplete physically to perform citizenship or autonomy; rather, the embodiment of such norms and practices does not provide the context of recognition and interactions in its structures and processes to allow for such individuals to participate in social life in a meaningful way. In "Liberal Strategies for Exclusion" Mehta argues that central to liberal theory is an embodiment of citizenship which grants the status of personhood, and the right to freedom and equality that comes with it, to those who meet the "anthropological minimum" (431). And so, there is a distinction between possessing the potentiality for the anthropological capacities to perform reason, autonomy, self-determination etc and "the necessary conditions for their political actualization"(430). The exclusionary impulse of liberal theory is activated in and through its mediation of the "distance between the interstices of human capacities and the conditions for their political effectivity" (430).

Through this horizon, the embodiment of difference is ostracised as deviancy or deficiency¹³ and dependents living with severe disability are cast to the margins of recognisability as political subjects. Butler argues that in order to “be a subject” one must comply with “certain norms that govern recognition” which make “a person recognizable”¹⁴. Individuals whose minds and bodies exist on the "limits of established norms" of embodiment and personhood are least recognisable. The central mediums for political participation, such as voting, civil disobedience, deliberation, not only assume an able-bodied citizenry with equal kinetic and mental competencies to perform but also cannot, by their very function, be fine-tuned to accommodate the fluctuating forms of responsiveness of each and every dependent. The capacity to be a recognizable subject, as determined by who is understood as a "living being, who lives or tries to live" and who exists on the margins of "established modes of intelligibility", determines the extent to which the individual is deemed worth of sheltering, existing and mourning¹⁵. By intelligibility, Butler implies a “readability in social space and time, an implicit relation to others (and to possibilities of marginalization, abjection, and exclusion) that is conditioned and mediated by social norms”¹⁶. Not all political subjects are equally visible, and those, who are already socially lost or socially dead, are tied

¹³Arneil, Barbara. "Disability, Self Image, and Modern Political Theory." *Political Theory* 37.2 (2009): 218-42. Web. 27 Feb. 2014. p.220

¹⁴Butler, Judith. "Performativity, Precarity and Sexual Politics." AIBR. *Revista de Antropologia Iberoamericana*.4.3 (2009). Print. p.4

¹⁵ Ibid.

¹⁶ Butler p.10

into knots without hope of ever becoming undone¹⁷. The process of subject formation, tempered by the "differential allocation of recognisability"¹⁸, places dependents in contexts of heightened precariousness.

And so, a politics of inclusion must be premised on "the ideal of a heterogeneous public" in which embodied difference is not only respected, but also, empowered as a political resource for social justice. In opposition to the association between extinction and exclusion is the symbiotic relationship between sustenance and empowered inclusion¹⁹ which illustrates the pivotal role of care in mediating the dissonance between 'deviant' bodies and the material world. In the context of disability politics, central to this task is dissolving the binary opposition between dependents and political subjecthood or agency through an affirmation of shared human vulnerability and marking environments, not bodies, as the problem to be worked on. Garland-Thomson's comparison of the socio-political and medical models of framing disability is a helpful heuristic to illustrate how the empowered inclusion of dependents can be realized by "changing the shape of the world"²⁰ and "exclusionary attitudinal, environmental and economic barriers"²¹

¹⁷ Butler p.13

¹⁸ Butler p.9

¹⁹ Young's definition of empowered inclusion as the basis of democracy is three-fold: 1)it ensures that "all legitimate interests in the polity receive expression", 2)it inspires individuals to "transform their claims from mere expressions of self-regarding interest to appeals to justice, and 3)it enlarges the "social knowledge available to a democratic public" which improves citizens likelihood in making "just and wise decisions" (Young, Iris. *Inclusion and Democracy*. Oxford: Oxford University Press, 2000. Print. p.115)

²⁰Garland-Thomson, Rosemarie. "Misfits: A Feminist Materialist Disability Concept." *Hypatia* 26.3 (2011): 590-609. p.598

²¹ Garland-Thomson "Integrating" p.14

instead of "changing bodies imagined as abnormal"²². The medical model frames disability as an "overwhelming tragedy" for dependents summoned to a life of frustration²³ and suffering²⁴. Therefore, it reduces "cultural tolerance for human variation and vulnerability by locating disability" in flaws of the body by focusing only on how to prevent²⁵ or cure disability²⁶. The socio-political model frames disability as: 1)a system for interpreting and disciplining bodily variations, 2)a relationship between bodies and environments, 3)a set of practices that produce both the able-bodied and the disabled and 4)a way of describing the inherent instability of the embodied self²⁷. The socio-political model of disability invites a rethinking of the body: its materiality, its politics, and its relation to subjectivity and identity²⁸.

Understanding disability as an "identity category and cultural concept" paves way for rethinking how we approach the question of "what it means to be human", the deconstruction of our relationships and the "experience of embodiment"²⁹. Garland-Thomson reconfigures the definition of misfit to illustrate that, like a "square peg in a round hole", the problem inheres within the

²² *ibid*

²³ Frustration, is however, common to

²⁴ Pfeiffer p.448

²⁵²⁵ In addition to 'pulling the plug' on those who survive bouts of illness and the elderly, the medical model also plays a role in preventing a different set of classes of disability from entering the world through reproductive technologies and termination of pregnancies. See "Live and Let Die? Disability in Bioethics" by Simo Vehmas " New Review of Bioethics, Vol. 1, No. 1, 145–157, November 2003

²⁶Garland-Thomson, Rosemary. "Integrating Disability, Transforming Feminist Theory." *NWSA Journal* 14.3 (2002): 1-32. Pg. 14

²⁷Garland-Thomson, Rosemary. "Integrating Disability, Transforming Feminist Theory." *NWSA Journal* 14.3 (2002): 1-32. Print. p.5

²⁸ Garland-Thomson "Integrating" p.9

²⁹ Garland-Thomson "Integrating" p.4

juxtaposition between flesh and world--or "awkward attempts" at fitting them together³⁰. However, if you shift the temporal or spatial context, the fit, and with it meanings and consequences, of the individual change too³¹. The visibility of dependents can be bolstered by transforming the meaning of their embodied identity to equip the bearers of their claims with a "coherent and positive narrative of human particularity" from which they can launch "subjective and political agency"³². Like the fish in the fish tank, the self materializes "in response to an embodied engagement with its environment, both social and concrete"³³.

Because the potential to acquire disability comes with life itself, we will always find ourselves on a scale of disability at different periods of our lives, at different points on the scale³⁴. Human beings are "intrinsically vulnerable"; and so, we cannot think of disability as a special, "unfortunate class of human beings...to which we do not belong"³⁵. Macintyre argues that "we are all disabled for extended periods" in our lives as infants, "when old and when ill or injured, physically or mentally"; and so, we are in a constant state of vulnerability to "further disability"³⁶. Political dependency theorists present vulnerability and

³⁰ Garland-Thomson "Misfits" p.593

³¹ Ibid

³² Garland-Thomson "Misfits" p.597

³³ Garland-Thomson "Integrating" 20

³⁴ Macintyre, Alasdair. *Dependent Rational Animals: Why Human Beings Need the Virtues*. Chicago: Routledge, 1999. Print. p.73

³⁵ Knight, Amber. "Disability as Vulnerability: Redistributing Precariousness in Democratic Ways." *The Journal of Politics* 76.1 (2014): 15-26. p.17

³⁶ Ibid.

dependency as avenues for universalizing the phenomenon of disability, something contained inside all of us, as a resource for an egalitarian political order.

Eva Kittay presents vulnerability as a tool through which charges can make legitimate moral demands for care. She notes that if we can “see each individual as nested within relationships of care, we can envision a relationship that embraces the needs of each”³⁷. Through a shift from individual-based equality to connection-based equality, we can depart from a rights-based discourse and ask the question:

What are my responsibilities to others with whom I stand in special relations and what are the responsibilities of others to me, so that I am well cared for and have my needs addressed even as I care for and respond to the needs of those who depend on me?³⁸

Through the understanding that everyone is “some mother’s child”, one is entitled to make a claim for relationships in which one can be cared for and for a “socially supported situation in which one can give care without the care-giving becoming a liability to one’s own well being”³⁹. In sync with Hobbes, Kittay identifies vulnerability as a definitive aspect of the “corporeal situation of the political subject”⁴⁰; however, for Hobbes, vulnerability should be repudiated because it

³⁷Kittay, Eva. *Love’s Labour*. New York: Routledge, 1999. Print. p.66

³⁸ Kittay p.27

³⁹ Ibid.

⁴⁰Whitney, Shiloh. "Dependency Relations: Corporeal Vulnerability and Norms of Personhood in Hobbes and Kittay." *Hypatia* 26.3 (2011): 254-73. p.557

“signifies an opportunity to wound”⁴¹; whereas, for Kittay, dependency should be affirmed because through it we can deepen human relationships through a recognition of our interdependence.

By universalizing disability as a side order of human frailty, Kittay’s dependency critique and the socio-political model, on their own, come off as too conflationary, and so, fall short in explaining how embodied difference manifests in the form of political inequalities and exclusion. Another shortcoming is that they fail to demarcate the differences between embodied difference and structural difference which prevents them from making the argument that the structural inequality revolving around disability cannot be universalized, as shared by all of us in our potential to acquire disability, because it is particular to the structural positioning and lived experience of individuals with disability, especially those in dependency relations. And so, here my argument departs from the dependency critique in that though we are moving on a plane of dependency from birth to death, the structural inequalities revolving around disability are not shared by all, but rather by persons with disability who exist on the margins of recognisability and constitute a unique minority group, structurally speaking. And so, the universal frame is only a helpful heuristic through which we can censure underwriting persons with disabilities’ claims to justice and personhood by showing the

⁴¹ Ibid.

relevance of their claims in remedying the democratic deficit and exposing structural injustice. This stems from the premise of empathic representation, the idea that if this could happen to anyone, then *their cause is my cause because I would not want to be treated as such if that were to happen to me or any of my loved ones*. The drawbacks of the dependency critique are circumvented by Butler and Young's attentiveness to structural power and embodied difference with their supplementary premise that vulnerability is not shared equally in a context of inequality.

Butler defines precarity as the “politically induced condition” of maximized vulnerability in which “certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence and death” and arbitrary state violence⁴². She argues that precarity manifests in two forms: material and perceptual. The latter refers to instances where some lives are “perceptually cast as destructible and ungrievable,” and through the horizon of hegemonic discourse “such populations are losable and can be forfeited because they are framed as being already lost or forfeited”⁴³. Dependents located in care facilities are exposed to perceptual precarity as their bodies are marked and medicalized--especially those recovering from acquired disability due to illness such as TBIs, strokes, Dementia, Alzheimer's etc. and are treated as already gone,

⁴² Ibid.

⁴³ Butler p.3

in the process of dying, or irrelevant. Butler illustrates how exclusionary norms of personhood obstruct the recognisability of dependents as political subjects, which in turn results in a differential distribution of precarity--exposing dependents and dependency workers to a higher degree of precariousness. And so, it is systems of representation and environments which disempower dependents, not embodied difference, corporeal vulnerability or disability in and of itself.

In specific, the structural positioning of dependency relations in relation to other groups and individuals disenfranchises dependents. Young illustrates how the precarity that flows from dependency and the corporeal vulnerability of the political subject is heightened in the context of structural inequality⁴⁴. At the heart of such inequality is Butler's politically induced maximum vulnerability which means there is structural, as well as embodied, difference. It is one thing to be treated like a disabled person, gendered body, but it is an entirely new ball game to be structurally disadvantaged and treated as such due to systems of representation which deem you unfit or lesser than and in Butler's sense, already forfeited. Once again, attitudinal and environmental barriers advise the processes of marginalization which cast the most vulnerable members of society to even more vulnerable positions; and what increases the risk of death, violence or injury is not the dependency or corporeality of the subject, but rather the lack of institutional

⁴⁴ Young defines structural inequality as the "relative constraints some people encounter in their freedom and material well-being as the cumulative effect of the possibilities of their social positions, as compared with others who in their social positions have more options or easier access to benefits" ("Inclusion" p.98)

support for relations of care--the primary means to sustenance for dependents.

Young defines persons with disability as a structural⁴⁵ social group relationally constituted “from the outside by the deviation of its purported members from normalized institutional assumptions about the exhibition of skill, definition of tasks in a division of labour, ideals of beauty, built environment standards, comportments of sociability” etc.⁴⁶. And so, structural difference is perpetuated “by a set of relationships and interactions that act together to produce specific possibilities and preclude others”⁴⁷.

An example of this is the case of marginals, “people the system of labour cannot or will not use”, who experience oppression in the form of being denied access to the resources, recognition or benefits of being part of the labour process⁴⁸. In “Five Faces of Oppression”, Young presents marginalization as the most dangerous form of oppression as it pertains to the exclusion of an entire category of people from useful participation in social life ⁴⁹. She critiques liberalism as presenting an exclusionary embodiment of citizenship which exposes dependents to “arbitrary and invasive⁵⁰ authority of social service providers”; and

⁴⁵Young defines a structural group as a “collection of persons who are similarly positioned in interactive and institutional relations that condition their opportunities and life prospects” (“Inclusion” p. 97)

⁴⁶Young, Iris M. “Structural Injustice and the Politics of Difference.” *Intersectionality Workshop-AHRC Centre for Law, Gender, and Sexuality* (2005). Print. p.12

⁴⁷Young “Inclusion” 93

⁴⁸Young, Iris Marion, “Five Faces of Oppression” *Philosophical Forum* 19 (1988) p.53

⁴⁹ Ibid.

⁵⁰ Coercion, deception or deprivation of important information by medical or care professionals through a “shut up we know best” approach often hinders capacity to make an informed choice about care increases potentiality for injustice and domination. The exercise of autonomous choice in the context of medical care pre-supposes that the patient: 1)has decision-making capacity, 2)is not impaired by a variety of factors that interfere with autonomous choice, 3)receives information about the risks and

in doing so, subjects them to “patronizing, punitive, demeaning and arbitrary treatment by the policies and people associated with welfare bureaucracies”⁵¹. In particular, medical and social services professionals are understood to “know what is good for those they serve” and the dependents do not have “the right to claim to know what is good for them”--granting the professionals a “sufficient warrant to suspend basic rights to privacy, respect and individual choice”⁵².

And so, dependents located in care facilities are treated as denizens or shadow citizens who compose a sort of capsular civilization. Characterized by Iris Young as external exclusion⁵³, structural inequality hinders dependents' capacity to participate in the fora of debate. This analogy of denizenship, shadow or prosthetic⁵⁴ citizenship allows us to imagine people who are “legally citizens but do not benefit from many of the rights associated with that status”⁵⁵. And so, dependents are positioned not only at the margins of personhood, but also at the margins of visibility as rights discourse is blind to the spatiality of disability in that it casts clients of care facilities to the peripheries of visibility in the identification of oppression, injustice and inequality by ignoring the “uneven material geography

benefits of options for care and 4)has the opportunity to question and receive answer in relation to issues involved in any decision⁵⁰. At the crux of this issue is the tension between the principle of autonomy and the principle of "beneficence"⁵⁰ which enables medical professionals to provide care to patient if he or she is incapable to express his preferences, values or beliefs for his betterment in the case of individuals in comatose states, severe traumatic brain injury etc. Oddi, Lorys. "Enhancing Patients' Autonomy." *Dimensions of Critical Care Nursing* 13.2 (1994).p.61

⁵¹ Young "Five Faces" p.50

⁵² Young "Five Faces" p.51

⁵³ Young "Inclusion" p.52

⁵⁴ Cresswell defines the prosthetic citizen as a person whose "capacities are intimately linked to his or her geographies (both material and imaginative) (260).

⁵⁵Cresswell, Tim. "The Prosthetic Citizen: New Geographies of Citizenship." *Political Power and Social Theory* 20 (2009): 259-73. Web. 27 Feb. 2014. p. 268

of power”⁵⁶. Care is an avenue through which dependents can develop alternatives to or means to navigating exclusionary spatial and material geographies.

Cresswell invites investigation into how care plays a role in geographies of mobility in reconciling and mediating mis-fits between the body and the world because geography is a "fundamental part of the process of reconfiguration"⁵⁷. This notion of reconfiguration is echoed not only by Garland-Thomson but also by, Kvigne and Kirkevold who argue that rehabilitative and supportive care facilitates the reconciliation and adjustment⁵⁸ process in cases of acquired disability post-illness. Kvigne and Kirkevold define the changes to the body experienced by individuals post-stroke as "re-embodiment"; echoing Garland-Thomson, they argue that through the practice of care, individuals can become "more familiar with the unfamiliar body" and "re-own their changing body" by learning how to "do different tasks or feeling comfortable" with the paralysis⁵⁹. And so, care is a crucial avenue through which the self-esteem of such individuals can be bolstered in an through the interactions between the dependent and the dependency worker. Relations of care compose the material geography of the dependent through which he exercises mobility. Cresswell's conception of prosthetic citizenship, as well as Kvigne and Kirkevold's idea of an extended body which relies on other persons or

⁵⁶Cresswell p. 270 Uneven material geographies refer to non-accessible spaces which spatially exclude persons with disability

⁵⁷Ibid.

⁵⁸ Kvigne, Kari, and Kirkevold Marit. "Following a Stroke Living with Bodily Strangeness: Women's Experiences of their Changing and Unpredictable Body." *Qualitative Health Research* 13 (2003): 1291-319. Print. p. 1302

⁵⁹ Kvigne and Kirkevold p. 1305

aids for mobility, illustrate that relations of care compose the material geography through which dependents mediate the dissonance between world and body.

Appeals to shared human vulnerability and dependency as essential to the human condition may counter this uneven material geography, recover the disabled from the status of denizen by helping to dissolve the able/disabled binary by framing disability as a “shared matter of political planning and public welfare”--as opposed to primarily a discrimination issue faced by Young's conceptualization of a distinct structural group⁶⁰. Such an approach is especially helpful in engaging intellectual discourse on moral personhood, agency and responsibility; it challenges us to redefine what it means to be human, and how the myth of self-rule hinders the visibility of dependents as persons worthy of protection. However, in order to bring the dependency critique from the realm of applied ethics into praxis and politics, it is imperative for it to account for the differential distribution of precarity and structural difference. This is where the role of care as an avenue for facilitating the empowered inclusion of dependents comes into play.

⁶⁰ Knight p.16

SECTION III: The Politics of Inclusion and Care

Having illustrated the connection between political exclusion and extinction or threats to existence, an association underlined by exclusionary systems of representation, I will now show how relations of care can be mobilized as a site for political representation due to the association between inclusion and sustenance. Tronto defines care as a "species activity" through which we "maintain, continue, and repair our world so that we can live in it as well as possible" which includes acts and relations of care which are nestled in a "life-sustaining web interwoven by bodies, selves and the environment"⁶¹, so that "no one is left alone"⁶². Care is more than an activity, it is a relational practice because it incorporates normative guiding values and temporally extends beyond a decision or a single act⁶³. And so, as a practice, care teaches us "how to respond to needs and why we should", bolsters "mutual trust and connectedness between persons" and makes humans "morally admirable"⁶⁴. Tronto and Fisher outline five phases of the practice of care: 1)*caring about* (identification of unmet needs) 2)*caring for* (acceptance of responsibility for care by individual or group to help meet those needs), 3)*care-giving* (acts of care work), 4)*care-receiving* (response from person thing, group, animal, plant or environment that has been cared for), and 5)*caring with* (how caring needs are met

⁶¹ Tronto p.2

⁶² Gilligan p.62

⁶³ Held, Virginia. *The Ethics of Care: Personal, Political, and Global*. Boston: Oxford University Press, 2006. Print. pg.37

⁶⁴ Held "Ethics of Care" p. 42

needs to be consistent with “democratic commitments to justice, equality and freedom for all”) ⁶⁵.

To supplement the five phases of care, Tronto offers the ethical values of: attentiveness, responsibility, competence, responsiveness and solidarity ⁶⁶. As will be discussed later through Saward's framework of representation, attentiveness, responsiveness and solidarity are particularly important in the claims-making process. Tronto's framework of care and its moral values illustrate that caring is not only a dyadic interaction between the dependent and the dependency worker, caregiver and care-receiver or the human body and the act of care, but it is also an on-going relational process of citizens as a whole within society and between structures and agents. Relations of care encompass the interactions and role-relationships between: the institution and the dependent, the institution and the dependent's family, the dependent and himself, the dependent and care professionals and the dependent and his family etc. From a structural analysis, the allocation of resources in terms of care work is “undervalued and ascribed to

⁶⁵ Tronto "Caring Democracy" p.22-23 and

⁶⁶ Attentiveness, aligned with caring about, flows from recognizing the needs that arise from dependency through “a suspension of one's self-interest and a capacity to genuinely look from the perspective of the one in need” ⁶⁶. Responsibility, aligned with caring for, is the acceptance and materialization of a relation of care through recognition of moral obligation to care for. Competence pertains to the “dirty work” of care, the actual care-giving; it is both a technical and moral issue ⁶⁶. Responsiveness, achieved through care-receiving, is characterized by the response from the person, group, plant, animal, environment that has been cared for; quality of care and meeting of needs is evaluated through the moral quality of responsiveness. The processes of evaluating response are contoured by the individual and his competencies as supported by family members, medical professionals, members of his care team etc and measures of response can range from a tear drop, a smile to verbal and kinetic engagement and expression in accordance with the physiological, cognitive, dialogical, emotional competencies of the dependent. The final quality of solidarity, developed by Sevenhuijsen, achieved through “plurality, communication, trust and respect”, includes critical moral qualities which “make it possible for people to take collective responsibility, to think of citizens as both receivers and givers of care, and to think seriously about the nature of caring needs in society” (Tronto p.35).

women and people of lower class and status"⁶⁷ In addition, because the need for care is ascribed to most vulnerable members of society, elderly, disabled, children etc. who are dependent, the allocation of power in care relations is placed in the hands of “those who are deemed competent and independent”⁶⁸. From a socio-economic standpoint, the wealthier you are, the better you are cared for and the “less likely that you are to be employed in doing care work for others”⁶⁹. And so, caring goes beyond the hands-on work that goes on between the caregiver and the care-receiver, it is also involves the “larger structural questions of thinking about which institutions, people, and practices should be used to accomplish concrete and real caring tasks”⁷⁰.

The socio-political model and the frame of shared human vulnerability knock down the idea of the disability as specific to the experience of a minority group⁷¹ and with it, narratives of tragedy and stereotypes of maladjustment--all of which perpetuate cycles of discrimination and structural difference against persons with disability. Disability does not make dependents vulnerable; lack of support for relations of care and the precarious structural positioning of dependents and dependency workers does. Yet, such vulnerability leaves space for empowerment. Though Kittay emphasizes dependence as an integral dimension of

⁶⁷ Tronto 99

⁶⁸ Ibid.

⁶⁹ Tronto 100

⁷⁰ Tronto 139

interdependence, her critique falls short in paving conceptual space for the empowerment or development of self-determination of individuals located in care facilities. The language of cure and rehabilitation runs through the narratives that explain the lived experiences of such individuals. And so, as problematic as it is to medicalize disability for the sake of remedying abnormalities, it is also problematic to valorize vulnerability as only entailing powerlessness through dependency. Kittay's approach only considers care in terms of the body's or mind's vulnerabilities, and not by the "development of its powers"⁷². For example, through relational autonomy and adaptation, the living body can acquire new powers, capacities and deeper relationships through which one can be empowered. As argued by Whitney, there are powers which are "consistent with vulnerability, even complicit with vulnerability" whose "development is inseparable from the adaptation and cultivation of specific vulnerabilities"⁷³.

Through the socio-political model, Garland-Thomson also argues that "subjugated knowledge", and the oppositional consciousness that arises from it can develop through the experience of misfitting⁷⁴. She presents misfitting as an opportunity for raising "intense awareness of social injustice" and mobilizing solidarity within a "community of misfits" through which we can achieve a more

⁷² Whitney p.570

⁷³ Whitney p.570

⁷⁴ Garland-Thomson "Misfits" p.592

"liberatory politics and praxis"⁷⁵. Echoing Garland-Thomson, Young argues that individuals should be understood as "positioned in social group structures"⁷⁶; those who are similarly positioned share a social perspective due to their "particular location-relative experience" grounded in a "specific knowledge of social processes and consequences"⁷⁷. Though dependency workers and dependents constitute separate structural groups, interactions and affinities between them provide insight into how relations between individuals in civil society can be mobilized to remedy structural inequalities.

Dependents are "agents of recognition" who through the very experience of misfitting "engage in challenging and rearranging environments to accommodate their entrance to and participation in public life as equal citizens"⁷⁸. Because their bodies do not conform to what is normal, what has been standardized to humanness, misfits can "yield innovative perspectives and skills in adapting to changing and challenging environments" through resourcefulness and adaptability induced by the interactive dynamism"⁷⁹ between flesh and the world. And this is what Garland-Thomson refers to as the "productive power of misfitting"⁸⁰. Kittay's valorization of dependency, as a corporeal situation, writes "vulnerability in

⁷⁵ Garland-Thomson "Misfits" p.597

⁷⁶ Young "Inclusion" 136

⁷⁷ Young "Inclusion" 136

⁷⁸ Garland-Thomson "Misfits" p.603

⁷⁹ Garland-Thomson "Misfits" p.604

⁸⁰ Ibid.

opposition to power”⁸¹. In order to capture an inclusive affirmation of personhood through the lens of shared human vulnerability, it is imperative to allocate conceptual space for the powers that manifest in and through the relations of care developed in contexts of precarity and for allowing persons with disabilities to articulate, challenge and rearrange their environments. And so, with the ethics of care comes an "ethics of resistance to moral injury"⁸² caused by misfitting as articulated by persons with disability for persons with disability.

Through the intrinsically relational practice of care, dependents not only sustain themselves, but they also develop a "repertory of skills" and competencies through which they achieve "self-discovery, self-definition and self-direction"⁸³. Thus, central to the challenge of designing a care-based model of political representation is understanding the role of interdependency and relationships in the self-determination of dependents. By unpacking the notion of self-determination implicit in the one citizen, one vote deflationary model of political participation, through the frame of relational autonomy, we can attribute interdependency a special significance in the process of political representation. In *Law's Relations*, Nedelsky presents relational autonomy as a category of analysis through which we challenge how space is regionalized in and through the dichotomies of collective-

⁸¹ Whitney p.573

⁸² Gilligan, Carol. "Moral Injury and the Ethic of Care: Reframing the Conversation about Differences." *Journal of Social Philosophy* 45.1 (2014): 89-106. Web. 21 July 2014. p.90

⁸³ Held "Ethics of Care" p.48

individual and public-private defined by an understanding of private property and the skin of the body as boundary-markers of autonomy. She argues that because relational autonomy is “well-suited to the problems of the modern welfare and regulatory state”, the state must make “dependence on state services and regulation consistent with it”⁸⁴

Political subjects, especially dependents, move in and through a relationship to the environment, to their contemporaries, to the past and to themselves. Such relations are constructive because the context of our situation enables or constrains our capacity to act and determine our will. At the center of the care critique of individual autonomy is a feminist⁸⁵ conceptualization of the self as “having both a need for recognition and a need to understand the other”⁸⁶; contrary to the master-slave dialectic, Held presents these needs as compatible. She argues that in relations of care both the dependent and the dependency worker “give and take in a way that not only contributes to the satisfaction of their needs as individuals but also affirms the larger relational units they compose”⁸⁷. At the heart of the ethics of care is the insight that the “self and other are interdependent”⁸⁸ and that the practice

⁸⁴Nedelsky, Jennifer. *Law's Relations: A Relational Theory of Self, Autonomy, and Law*. Boston: Oxford University Press, 2011. Print. p. Abstract to Chapter 3

⁸⁵ In *In A Different Voice*, Gilligan argues that in terms of masculinity, adulthood and maturity is achieved by gaining the capacity for autonomous thinking, clear decision-making, and responsible action; whereas, in the domain of femininity, adulthood or womanhood starts from the “interdependence of love and care” (17). The former favours “separateness of the individual over connection to others” (17). And so, in the context of care, maturity and the development of relationships are measured perspective of quality traditionally attributed to femininity.

⁸⁶Held, Virginia. *Feminist Morality: Transforming Culture, Society, and Politics*. Chicago: University of Chicago Press, 1993. Print.p.60

⁸⁷ Ibid.

⁸⁸ Gilligan p.74

of care "enhances both others and self"⁸⁹. And so, maintaining the larger relational unit "becomes a goal" in which progress is not measured by the level of individual autonomy achieved by the dependent. Rather, the health of the relationship is evaluated in terms of "competence in creating and sustaining relations of empathy and mutual intersubjectivity"⁹⁰.

In sync with dependency theorists, Nedelsky argues that independence is not a "core dimension" of the principle of autonomy because autonomy is realized through constructive relations which include intimate, cultural, institutional and ecological forms of relationships. And so, the state's role should be to "structure relations so that they foster autonomy" instead of creating the conditions within which individuals can actualize a "mythic independence"⁹¹. Through the practice of care, dependents can work with dependency workers to create a "reasonable fit in a reasonably sustaining environment"⁹². Garland-Thomson argues that a "fit" occurs when a "harmonious, proper interaction" takes place between "a particularly shaped and functioning body and an environment that sustains that body"⁹³. In line with Cresswell's notion of prosthetic citizenship and geographies of mobility, as well as Kvigne and Kirkevold's notion of the extended self, the aim of dependency work is to discover, invent or mobilize potential spatial or temporal points of

⁸⁹ Ibid.

⁹⁰ Ibid.

⁹¹ Nedelsky p.119

⁹² Garland-Thomson "Misfits" p.596

⁹³ Garland-Thomson "Misfits" p.594

encounter between the dependent's body and the world in order to develop particularized avenues for realizing his self-determination in and through the context of his positioning, competencies and desires.

In addition to Nedelsky's presentation of autonomy as a category of analysis, Arneil offers five strengths of affirming interdependency as part and parcel of the human condition. She presents the following as advantages of understanding the lived experience of individuals with disability through this frame: 1) disability as flowing from interdependency, instead of incapacity to perform independence, deconstructs the binaries between “autonomy/independence/justice versus disability/dependency/charity in modern political thought”, 2) it reconfigures disability as “not as an individual deficit...but as an interdependent product of disabled individuals' physical/mental limitations in relationship to the physical, social, and political environment they must navigate on a daily basis”, 3) it extends the gaze of the political and ethical theory to problematize the “asymmetrical relationship between caregivers and care-receivers by rethinking the charge as interdependent client, rather than a wholly dependent child, 4) its redefinition of interdependency as a “constellation of supports required by all of us to gain independence” and 5) its challenge to the dominant narrative of tragedy used to explain the experience of dependents located in care facilities by presenting

acquired disability as a “dimension of human diversity”⁹⁴. Arneil’s use of interdependency and the socio-political model to frame disability pave conceptual space for engagement with how relations of care can be mobilized in the process of representation. The frame of interdependence “pushes us beyond “some mother’s child”, Tronto's “client” or Kittay's “charge”. Through an affirmation of the role of relationality in the exercise of self-determination, the image of the care-receiver as a “citizen with rights” can be surfaced⁹⁵.

To be autonomous is not merely an exercise of personal bodily performance of reason and rationality, rather it also developed in and through structures of power and patterns of relationships. Nedelsky, Arneil and Young invite investigation into the role of the physical, social and linguistic environment and more specifically, institutional design in structuring the relationship between dependency workers and dependents in a way that lessens the precarity that flows from their structural positioning. They dissolve the binary opposition between dependency and powerlessness by illustrating how interdependency is symbiotically connected to the self-determination and self-development of individuals. In specific, their frameworks allow for vulnerability, as a pre-condition for the need for care, as a context through which relational affinities can be

⁹⁴ Arneil " Disability" p. 234

⁹⁵ Arneil " Disability "p.236

nurtured for the sake of increasing the recognisability of dependents as political subjects worthy of demanding accountability.

However, with relational autonomy comes the potential for relational marginalization. Dependency workers and dependents share the benefits and burdens specific to the nature of their social cooperation because of the act of care's closeness to the human body which requires them to physically occupy the same spatial and structural positioning; together they constitute the netherworld of dependency relations at the margins of public accountability. Kittay argues that the state of the dependency worker herself is a secondary state of dependence because by taking on the responsibility of caregiver her Self “defers or brackets its own needs in order to provide for another's”⁹⁶; and in doing so, the dependency worker becomes a transparent self who “sees first the needs of another” before her own. Though such selflessness could help to facilitate “deep friendships, intimate relations, a less exploitative relation to the natural world”, it also makes the dependency worker reliant on a provider for access to “the external resources necessary to maintain herself, the dependent, and the relation”⁹⁷. In addition to the needs of the dependent, the dependency worker must also sustain the relation for “her self-understanding as a morally and socially worthy person”⁹⁸. Young carers,

⁹⁶Kittay p.46

⁹⁷Kittay p.51

⁹⁸ Ibid. See also, Gilligan p.17 This stems from the feminist notion that women evaluate their self-worth through contexts of human relationships and their ability to care for others.

for example, not only report high levels of stress, lack of stability and social isolation as a result of the unpredictability of their world but also, report positive outcomes from their care-giving roles such as heightened sense of self-worth, maturity, selflessness, compassion and levels of responsibility⁹⁹. By taking on an “adult-role” of care-giving in order to help their family survive or get by, young carers must sacrifice to some extent their own social and professional development to focus on their responsibilities at home¹⁰⁰.

The problem here is that the dependency worker-dependent relationship is outside the parameters of the private-political compartmentalization of human activity. And so, in this unique context, where a person is reliant on representatives of the state for toileting, eating etc., though the personal is highly political such activities are excluded from Arendtian spaces of appearance. Therefore, the neoliberal justification of the private-political dichotomy in discussing the limits of government power deepens the “circles of unequal care”¹⁰¹. In order to rethink the role of care in democracy, the public/private dichotomy, an “outdated inheritance from Western Political thought”¹⁰², needs to be reconfigured to account for the role of interdependency in the exercise of self-determination. Theorizing the political as extraneous to the sphere of intimacy, through the private-political

⁹⁹ Charles p.28

¹⁰⁰Stainton et al.p. 48

¹⁰¹ Tronto p.97

¹⁰² Tronto p.1

dichotomy, disempowers those involved in relations of care through a compartmentalization of human activity that relies on an exclusionary definition of autonomy.

SECTION IV: From the Outside Looking In: Stay Close and Pay Attention!

But the question remains, how can we translate the theory of relational autonomy into material institutional mechanisms through which the claims of dependents can be brought into arenas of political action? The answer is that it is less about bringing the claims from inside dependency relations out into the world of politics and more about infiltrating relations of care with the politics of presence and facilitating political inclusion and recognition from within the relationship. This task demands an interrogation into the ontology of political representation itself. Young argues that “rather than a relation of identity or substitution”, political representation “should be thought of as a process involving a mediated relation of constituents to one another and to a representative”¹⁰³. Thus, there are two avenues through which individuals can be represented; and the former invites investigation into mobilizing relations within civil society, especially those as intimate and as close to the body as relations of care, as instrumental to the claims-making process. Through this frame, Young deconstructs representation as one representing the many and configures it as a “differentiated relationship among plural actors”¹⁰⁴. Not only should the representative be both separate and connected to his constituency, but the constituents “should also be connected to one

¹⁰³ Young "Inclusion" 127

¹⁰⁴ Ibid.

another”¹⁰⁵. Through this frame of relationality, we can assign the inter-group affinities between dependents and dependency workers, rooted in their shared structural positioning, a vital role in the process of representation.

Central to the challenge of designing a care-based model of representation is pluralizing the modes and sites through which the voices of the “people” from all corners, crooks and crannies of society are collected, mediated and addressed. In *The Representative Claim*, Michael Saward presents political representation as an “on-going process of making and receiving claims--in, between and outside electoral cycles”¹⁰⁶. He presents representative democracy as “not so much a given set of institutions as a design challenge”¹⁰⁷ which dares us to imagine and creatively stretch our understanding of it to include different forms of representation, descriptive, expressive, elective etc by exploring the “shape and dynamics of complex representation”¹⁰⁸. Saward frames representation as a “dynamic quality of society” as opposed to a “fixed quality of state” and therefore, the embodiment of political citizenship needs to be “unshackled as an idea” in order to “encompass the latent potential of citizen self-representation and participation in multiple sites of representation in an open society”¹⁰⁹. He presents representation as a “creative, ongoing and constitutive process” through which

¹⁰⁵ Young "Inclusion" p.132-134

¹⁰⁶ Saward, Michael. *The Representative Claim*. New York: Oxford University Press, 2010. Print. p.36

¹⁰⁷ Saward p.167

¹⁰⁸ Ibid.

¹⁰⁹ Ibid.

claims of identity, interprets and their reception by constituents and audiences are mediated. He argues by making representative democracy strange, it becomes “less a thing” and “more a complex aspiration”¹¹⁰.

Underlining Young’s consideration of inter-group relationships as vehicles of representation, Saward argues that representation is not “just there” as a thing, it is made, constructed, “by someone for someone and for a purpose” and through the mode of “its constructedness” the form it takes is qualified ¹¹¹. Therefore, the forms and manifestations of representation should be questioned, not representation as a model itself¹¹². Echoing Young, he argues that representation is a “relational process over time” which should be constitutive of diverse and shifting perspectives collected from groups and individuals located at different positions across the social field¹¹³. Also, representation does not just happen, its relational character implies that it is constituted by a maker, a subject, an object, a referent and an audience. He frames representation as: “a maker of representations puts forward a subject which stands for an object that is related to a reference and is offered to an audience”¹¹⁴. Saward argues that representative claims can “activate

¹¹⁰ Saward p.168

¹¹¹ Saward p.13

¹¹² Saward p.17

¹¹³ Saward p.28

¹¹⁴ Saward p.36

and empower recipients or observers, even if that is not the intention of the makers” because through claims recipients appear on the map¹¹⁵.

In the context of dependency relations, Saward’s framework can be mapped onto Tronto’s five phases of care to further illustrate how relations of care can be conceptualized as sites for political representation. The subject of the claim is whether the dependent has access to quality care, and how his needs can be better addressed, as determined by each individual’s particular experience--evaluated through responsiveness. The object is both the material act of care-giving, distribution/allocation of resources which influence access to care and the structural relations which mediate relations of care. The maker is the dynamic relationship between the dependent and the dependency worker. The referent is the dependent whose care is referred to in the process of claims-making. And this claim is offered to a specific audience: the dependent’s future self, the dependency worker, healthcare professionals, care and medical bureaucracies, municipal and provincial political representatives and policy-makers in healthcare, and the general public writ large.

There are three levels of audience here: the inter-temporality of the Self, those situated in the dependent’s context of immediacy and those involved in the political decision-making processes which shape the structures and relationships of

¹¹⁵ Saward p.55

power which influence the dependent's individual capacity to express political will. The latter includes the public writ-large because the task of caring about and caring with requires collective affirmation of the moral responsibility to support relations of care and dependents due to the universal corporeal vulnerability of the political subject. In regards to self-representation, through responsiveness, the dependent should have to whatever degree possible influence over determining how he is cared for in the future. In addition to pluralizing the modes and sites of representation, a care-based model of political representation also requires incorporating within institutional design mechanisms of attentiveness to account for bodily and cognitive variations.

Only through an attention to particularity, through proximity, can models of representation account for the specific forms of responsiveness used by dependents to exercise self-determination and political will through relations of care. In *Democratic Legitimacy: Impartiality, Reflexivity and Proximity*, Pierre

Rosanvallon sets up a continuum between the pole of generality, composed of rules, and the pole of particularity, solicitous attention, to illustrate how political action and will is legitimized by increasing the complexity of democratic forms and its subjects. He argues this can be achieved by both pluralizing the modes and sites of representation (through multiplication of generality and attention to particularity), and by restoring the temporal dimension of political representation

by accounting for intertemporality in institutional design. No longer can we get away with a homogenous image of *the people have spoken* which emerges at the electoral moment every four years. In agreement with Saward and Young, Rosanvallon argues that such a deflationary, one citizen-one vote model of political representation stifles investigation into who is to be represented, in what issues and whether one model fits all, and so on its own, is not equipped to legitimize political action due to its inability to capture an inclusive and diversified image of the whole.

Interestingly, he argues that “constructing a history, like managing the present” requires articulation of “different relations to social time”: the temporality of memory, the time-structure of human body, the *longue duree* of constitutional law, the time of a parliamentary mandate and the short-term of public opinion¹¹⁶. Only through a pluralisation of its modes and sites can political representation account for the interests of those who are absent from the present moment but are still influenced by the consequences of the politics of the present: intergenerational interests, our future-dependent selves (as we are all temporarily able-bodied and subject to the disability and dependency that comes with age, illness or happenstance), the environment, animals etc.

¹¹⁶Rosanvallon, Pierre. *Democratic Legitimacy: Impartiality, Reflexivity, Proximity*. Oxford And Princeton: Princeton University Press, 2011. Print p.133

Complementing Young's notion of differentiated solidarity, Rosanvallon argues that the construct of the people, refers to an “ever changing and invisible community of those whose suffering is ignored, whose histories are not taken into account”¹¹⁷. Political representation is the remedy to those suffering in silence. Only through the affirmation and recognition of grievances through political process can we lessen the precariousness that flows from the corporeal vulnerability of the political subject. Repeating Butler, Rosanvallon argues that if a framework of representation marginalizes individuals due to their locatedness at the margins of personhood, then they feel abandoned and what is at stake here is “not just their interests but their very existence”¹¹⁸. In order to represent someone in a situation of abandonment or suffering, one has to be “present at his side and make sure that society acknowledges his story” through empathic representation¹¹⁹.

Rosanvallon presents empathic power, in line with Young's presentation of perspective, as an answer to the crisis of representation through which legibility and visibility can be restored in political action¹²⁰ in a modern era which has “lost touch with the senses”¹²¹. By “pluralizing the modes and sites of representation”, models of representation can account for aspects of a “person's life experience, identity, beliefs, or activities where he or she has affinity with others” instead of

¹¹⁷ Rosanvallon p.189

¹¹⁸ Ibid.

¹¹⁹ Rosanvallon p.190

¹²⁰ Rosanvallon p.191

¹²¹ Ibid.

trying to “make individuals present in their individuality”¹²². Through this shift, we can invite investigation into representation of dependents through relations of care as opposed to struggling with the dead-ended question of how to make their individuality consistent with the forms of political participation available through the hegemonic discourse.

The dynamism between the productive powers of dependency, of misfitness, and the rare intimacy of the dependency worker-dependent relation, presents an interesting opportunity for political expression. Sharing a social perspective engenders group solidarity by giving each individual “an affinity with the other’s way of describing what he experiences”¹²³. Perspectives can be reified through story, song, play etc. Unlike the representation of opinion or interests, representation of perspectives need not be outcome-oriented; the aim is to promote “certain stand-points for discussion”; from within a specific social perspective, a representative asks “certain kinds of questions, reports certain kinds of experience, recalls a particular line of narrative history, or expresses a certain way of regarding the positions of others”¹²⁴. Young's perspectives-based model and Rosanvallon's empathy-based model of representation can be synthesized to produce a care-based model of political representation. Such a model could increase the recognisability

¹²²Young "Inclusion" p.133

¹²³ Ibid.

¹²⁴ Young "Inclusion" p.137-138

of dependents by activating inter-group affinities between dependency workers and dependents in the claims-making process.

What Young identifies as differentiated solidarity¹²⁵, in which inter-group and intra-group affinities and perspectives are mobilized in the representation process, is echoed by Bhattacharyya in his discussion of community development. His three core principles of community development, self-help, participation and felt-needs, provide insight into how the practice of care, because it works in and through the dependent's particular context and corporeal situation, is an ideal avenue through which dependents can acquire authorship in the process of claims-making and defining their needs. Branching from this line of thought is the independent living movement in disability politics which seeks to facilitate political inclusion of individuals with severe disability in and through policies and structures such as accessible housing, independent living communities, individual funding, care-support services etc.¹²⁶ This is given that the principle of self-help, in particular, which Bhattacharyya presents as the "opposite of dependency", underlined by the normative claim that "people ought to be self-reliant", does not deny the reality of interdependence. Rather at the heart of this principle is the ideal that people should learn to "solve their own problems" through the help and

¹²⁵ An alternative ideal of political inclusion which aims to promote individual freedom through community solidarity and relies on the freedom of association. It affirms that groups "dwell together whether they like it or not" within "a set of problems and relationships of structural interdependence" that impose on them moral obligations. Young "Inclusion" p.197

¹²⁶ Though the aim of this paper is to dissociate the binary between dependency and political subjecthood through the frame of relational autonomy, the arguments presented here share the basic tenets of the movement.

support of the community developer; the care-giver in this scenario is to "engage the people concerned in a process so that they themselves can identify what the problems are so that they own the problems"¹²⁷. He presents agency, which he defines as "the capacity to create, reproduce, change, and live accordingly" to one's "meaning systems, the power effectively to define" oneself "as opposed to be being defined by others"¹²⁸, as essentially a matter of self-definition. The capacity to define your own problem is the second principle of felt-needs: making intelligible your needs to yourself and communicating it to others. And the final principle of participation entails "taking part in the production of collective meanings, and not exclusion from it"¹²⁹.

At the crux of these principles, as appraised by the Independent Living movement, is the premise that dependents should mobilize their interdependencies and relations to actualize conditions for achieving greater authorship in the claims-making process by learning through the care of others how to define and solve their own problems by themselves to whatever extent possible. In sync with Young on her definition of social justice, I argue that institutional design and challenging the ontology of political representation can assist in creating the institutional and structural conditions necessary to develop and exercise the capacity for self-

¹²⁷ Bhattacharyya, Jnanabrata. "Solidarity and Agency: Rethinking Community Development." *Human Organization* 54.1 (1995): 60-69. p.63

¹²⁸ He presents agency as antithetical to dependency which he frames as a "condition devoid of any internal dynamic" Bhattacharyya p.61

¹²⁹ Bhattacharyya p.63

definition. Independent Living policy models are a potential manifestation of care as a site for political representation of dependents; however, the normative claim that individuals should aim to be as independent as possible, as if the value of self-reliance, in opposition to dependency, maps onto the concept of agency, undermines the role of relationships as constitutive of geographies of mobility and integral to self-determination and the role of allies and dependency workers, individuals outside the community of persons with disability, as potential messengers or advocates (for both individuals and for the community). The scope of my argument is how we can increase authorship for the sake of political inclusion by increasing the recognisability, not independence, of dependents with severe disability as political subjects.

Nonetheless, echoing Kvigne and Kirkevold's discussion of re-embodiment, authorship and the capacity for self-definition is realized through the practice of care which can result in higher likelihood to be self-reliant and exercise self-help. Unlike the Independence Living movement, in this paper I do not place independence as a normative project because it would underwrite the particular experience and struggle of individuals, regardless of accessibility, rehabilitative care and accommodation, who just cannot fit the "one person, one vote model" on a macro level; unless, the very construct of independence is reconfigured to account for human variation in geographies of mobility and relational autonomy in

contexts of dependency. As Kittay's dependency critique undermines the empowering features of dependency and vulnerability, the Independent Living movement falls short in affirming the opportunities for trust-building, mobility and innovation that can flow from contexts of relying on each other. However, the latter goes further than the welfare model and presents the charge as a citizen first, and medical or care service consumer second. The governance structures, ideals of self-determination and inclusion, self-definition in felt-needs and particularized forms of responsiveness of the movement are in sync with the core premises of this paper. Independent Living communities are an ideal setting in which inter-group and intra-group affinities can be fostered for the sake of solidarity and relational autonomy.

Bhattacharyya's notion of self-help, felt-needs and participation, at the heart of the Independent Living movement, illustrate how self-determination (independence, in his sense) can be realized through contexts of interdependency. However, the aim of this paper is to explore how we can establish favourable institutional conditions for self-determination, self-definition and self-development by empowering relations of care and shield dependents from the differential distribution of precarity. The fluctuating corporeal situation of the political subject, which is especially the case for those reliant on 24/7 on-site care supervision, asks of power to "express itself through body language and the ability

to project sensitivity and embody emotion¹³⁰. And so institutional design must contain within itself mechanisms which account for the reality of human frailty and bodily variations in its calculation of institutional performance¹³¹. In other words, relations of care are reflexive mechanisms through which power's distribution via institutional design can be checked and held accountable by those whose bodies are at the margins of the norm of personhood. The aim is to make power sensitive to the lived experience of most vulnerable by asking of it to engage with them on their terms and through the context of their corporeal situation.

¹³⁰ Rosanvallon p.190

¹³¹ I am not solely referring to the likes of power of attorneys, living wills etc.; rather, designing the form of paperwork, methods of interaction, making spaces accessible beyond the wheelchair ramp, sensitivity-training to particular situations, in-home service representatives, welcoming atmospheres, asking what the needs and forms of responsiveness of the individual are and working in and through the context of dependency etc. are ways through which institutions can respect the lived experiences of dependents in relations of care.

SECTION V: Reconciling the Politics of Presence with The Physical through Care

Central to the task of incorporating sensitivity to relations of care in institutional design is the reconciliation of the politics of presence with the physical (the corporeal situation of the political subject): designing institutions in a way maintains an ever-present, ear to the ground, process of representation between the representative and the represented, which is also, fine-tuned to the particularity of the individual's structural positioning, the changing human body, perspectives etc. Rosanvallon's argument that no one should be sacrificed at the “altar of abstract principle”¹³² echoes Gilligan's quest to “to turn the tide of moral discussion from questions of how to achieve objectivity and detachment to how to engage responsively and with care.”¹³³ The politics of presence demands physical proximity, attentiveness to particularity and a display of concern. Presence, itself, invites investigation into how we can expand the “realm of political action” through new forms of representation¹³⁴. Proximity, which focuses on quality of interaction, is defined by Rosanvallon as a “form of effort, which has both cognitive and informational dimensions”¹³⁵ which structures processes of “permanent exchange” between both society and government and individuals

¹³² Rosanvallon p.185

¹³³ Gilligan "In a Different Voice" p.xix

¹³⁴ Rosanvallon p.201

¹³⁵ Rosanvallon p.214

themselves. In the context of care, dependency workers, which includes family and friends, are usually the only ones ever-present in the lives of dependents and so, are uniquely proximate and qualified in understanding the needs, claims and competencies as they fluctuate with the dependents' bodies.

In addition to physical proximity, and on the same page as Tronto's moral qualities of care, another appropriate avenue for channelling the claims of dependents through the politics of presence is attentiveness to particularity. Echoing Butler, Rosanvallon argues that the “vulnerability to humiliation and rejection” unique to the context of precarity of dependents with severe physical and neurological disability and dependency workers is akin to the exploitation as a “fundamental aspect of the denial of humanity”¹³⁶; and so, power is affirmed as legitimate if it is “attentive to individual situations and makes the language of recognition its own”¹³⁷. A care-based model of political representation demands that institutions can care about each individual by legitimizing their actions through attentiveness to the “particularity of each situation”¹³⁸. And this is why Martha Nussbaum's idea of guardianship or proxy votes does not go far enough. She suggests that for individuals whose cognitive disability is so “profound” procedures should be designed to “authorize” guardians “to vote in that person's

¹³⁶ Rosanvallon p.178

¹³⁷ Rosanvallon p.179

¹³⁸ Rosanvallon p.172

interest and serve on a jury when that person's name comes up" because the "very presence of the surrogate...serves to give due recognition to the person with a disability, and to people with disabilities more generally"¹³⁹. Though Nussbaum presents an interesting model for bringing the claims of dependents into spheres of political action, her approach falls short in expanding the ontological horizons of political representation to account for relational autonomy: self-determination qua interdependency. Though some individual cannot attend jury duty or vote, due to profound cognitive or physical disability, they still are engaged through relations of care for their sustenance in claims-making regarding their own care and needs. A care-based model of representation must go beyond mere surrogacy and engage the dependent on his terms and his corporeal situation. Nonetheless, guardianship is a possible puzzle piece in the solution because it demands of institutional design to account for relational persons. As Rosanvallon argues, through inclusive modes of political participation, individuals must be "valued in their own right, for themselves" and as "subjects, who are important to others and count as members of a group who are worthy of specific attention"¹⁴⁰. This quality of attentiveness,

¹³⁹ Nussbaum's framework is closely aligned with the trusteeship model used by the Ontario Disability Support Program and Alberta Human Services. Whether its informal or formal trusteeship or an enduring power of attorney, public trustees are authorized to manage the finances of individuals with mental disability. Trustees can be family members, representatives of care facilities, friends or even community and religious organizations. Nussbaum, p.93 Nussbaum, Martha. "The Capabilities of People with Cognitive Disabilities." *Cognitive Disability and its Challenge to Moral Philosophy*. Ed. Eva Kittay and Licia Carlson. N.p.: Blackwell Publishing Ltd and Metaphilosophy LLC, 2010. 75-97. Print.

¹⁴⁰ Ibid.

which echoes Tronto's form of caring about, flows from the constructive relationship between the individual's solidity and institutional performance.

The link between the well-being of the individual and institutional performance is interesting especially in the context of care facilities where recovery and rehabilitation of individuals is highly determined by levels of support, trust, respect and friendship received through relations of care. In *The Priority of Democracy: Political Consequences of Pragmatism*, Knight and Johnson argue that the priority of democratic institutions should be second-order tasks such as the “monitoring, assessment and maintenance of the conditions necessary for effective institutional performance”¹⁴¹. Central to maintaining such conditions is mobilizing second-order tasks through bureaucratic institutions to dissolve factors which constrain the capacity of individuals to exercise political choice through an attention to particularity. And by conditions they are referring to the social prerequisites for the legitimacy of the institution itself, without which it cannot function efficiently or effectively. Echoing Young on structural inequality, Butler on the differential distribution of recognisability and Rosanvallon on the connection between inclusion and survival, Knight and Johnson argue that the institutionalization process must be grounded on the social precondition of the dignity and respect of each individual. Through this activity, political actors can be

¹⁴¹Knight, Jack, and James Johnson. *The Priority of Democracy: Political Consequences of Pragmatism*. Princeton: Princeton University Press, 2011. Print. p.188

prohibited from “taking advantage of the asymmetric distribution of resources in society within the domain of democratic decision making itself”¹⁴².

In order to explore how reflexivity can be mobilized through relations of care, it is important to investigate the factors which affect individual choice and negatively influence the “potential effects of participation on the collective outcome”¹⁴³. And such a task demands investigation into the context of the participant's activity, as well as into the “set of claims about the effects of various factors on the exercise of political choice”¹⁴⁴. Knight and Johnson ask, “what effect do these limitations on capacities have on effective institutional performance?”¹⁴⁵ because lack of capacity to participate due to inadequate forms of representation or socially recognized structures for inclusion, lessen the “diversity of inputs necessary for effective performance” and “distort the testing of ideas” by empowering those who enjoy the “advantages of the relevant capacity”¹⁴⁶.

Interestingly, they present institutional mechanisms as remedy or vehicle for facilitating conditions for experimenting with and creating inclusive forms of political participation. They argue that this suggestion goes beyond the present

¹⁴² Knight and Johnson p.188

¹⁴³ Knight and Johnson p.201

¹⁴⁴ Ibid.

¹⁴⁵ Knight and Johnson p.234

¹⁴⁶ Knight and Johnson p.160

form of protections against the power and resource advantages which flow from “non political contexts” in the political arena¹⁴⁷.

In order to holistically approach the problem of empowered inclusion and political participation, the problem of “adequacy of capacity” must be addressed with the “issue of the equality of capacity”¹⁴⁸ because equal opportunity of political influence “also requires that each individual have a real opportunity for influence”¹⁴⁹. Knight and Johnson also present institutional experimentation, which requires free and equal participation in democratic decision making, as an avenue through which all individuals can gain non-coerced access to arenas of political participation. In the context of the relations of care, especially those encapsulated in care facilities, every interaction between the dependent and the dependency worker presents an opportunity for experimenting with new forms of responsiveness and participation which challenge the able-centric and individualist embodiment of self-determination. Knight and Johnson, as well as Kittay and Tronto, argue that better caring results in a healthier democracy.

Only through an attention to the particularity of an individual's situation and physical reality can dependency workers work with the dependent to make representative claims constitutive of their shared experience. And because the time-structure of the human body influences the nature of dependency to range

¹⁴⁷ Knight and Johnson p.226

¹⁴⁸ Knight and Johnson p.235

¹⁴⁹ Ibid.

over time, through the relation of care, the dependency worker is constantly engaged with adjusting the activity of care to suit the needs and capacities of the individual.¹⁵⁰ The process of representation, as exercised through the activity of care, must be as fluid as the move from wheelchair, to walker, to cane, to one's own legs—whatever the shifts in capacities may be for the dependent, the dependency worker adjusts her care through attentiveness. Relations of care present an abundance of opportunity for experimentation with new forms of responsiveness which can be mobilized in the quest to establish a care-based model of political representation of individuals with severe physical and neurological disability. Repeating Knight and Johnson, Rosanvallon argues that, institutions which perform in an “attentive and respectful way can reinforce the self-esteem and identity of the people with whom it deals” and so, the “stronger the (proximate, impartial) institution, the stronger the individual”¹⁵¹.

The old demand of representativeness has been supplanted by the new expectation that governments demonstrate “the ability to share, to pay attention to the problems of ordinary people, and to display sensitivity to the trials and

¹⁵⁰ For example, in the first few weeks post-stroke my father was fully paralyzed and the only form of responsiveness available to us was the increase or decrease in his blood pressure level in reaction to changes in medicine. In a few months, as he regained movement in his neck, through communication we established the nod for yes form of responsiveness. In this stage, we could not ask him to move his neck to the left or right, or twice up and down to indicate consent because it was not clear if the concepts of left, right and numbers were sensible to him. And we chose nod for yes, as opposed to nod to express no, because imperative to patient recovery is a sense of power over the decisions influencing the maintenance of his well-being—or in a brute sense, what is done to his body by medical technologies and professionals. After a year now, we are still experimenting with new forms of responsiveness as his capacities change.

¹⁵¹ Rosanvallon p.176

tribulations of everyday life”¹⁵² through second-order tasks which occur in and through relationships between the individual and the institution, between individuals and the human body and the practice of care. In other words, “being present has become more important than making present”¹⁵³. The shift from making present to being present flows from a relational understanding of representation as an on-going process between the constituents and representatives facilitated in and through various modes and sites of representation beyond the electoral moment

¹⁵² Rosanvallon p.188

¹⁵³ Ibid.

SECTION VI: Conclusion

The practice of care as a mode of representation, need not be ends-oriented; it can be mobilized for the sake of promoting consciousness-raising and claims-making between those in dependency relations. And although individuals with severe disability may lack the resources or competencies to participate in the contexts of recognition and interactions for meaningful political participation as provided by prevailing set of social arrangements, dependency workers can still be mobilized as advocates, not surrogates, for their claims. In summary, the paper's argument unfolded in two stages: in the first stage, I reframed the issue at hand, and in the second stage I presented a potential avenue for recourse. First, I dissociated disability from powerlessness by illustrating that the lack of institutional support for relations of care and exclusionary systems of representation, as opposed to the corporeal vulnerability of the political subject, are what disempower dependents with severe disability. What makes dependents vulnerable is not the extent to which their bodies vary from norms of embodiment or their dependency on others for survival; but rather, how such norms influence the differential distribution of structural power and place dependents in contextually precarious positions and scenarios. And so, vulnerability flows from context, as determined by structural positioning; because dependents are differentially exposed to the risk of injury, arbitrary violence, or death, due to their

positioning, they are more vulnerable than other members of society. At the crux of this problem, which is also the missing puzzle piece between the problem and the way out, is the association of political exclusion and marginalization with extinction and political inclusion and recognition with survival and sustenance. Because dependents rely on relations of care for their sustenance, and rudimentary survival, in order to increase the recognisability of dependents as political subjects, it is imperative to understand relations of care, like mobility aids , as an extension of the body through which individuals exercise self-determination and remedy the disharmony between the world and their bodies.

And so, secondly, I argued that the multi-dimensional practice of care, because of its intrinsically relational character, is a political resource through which dependents with severe disability can exercise a greater degree of authorship and self-definition in the claims-making process. Central to this task is mapping the alignment between the values of attentiveness and responsiveness, at the heart of the ethics of care, and what democratic representation draws its legitimacy from: proximity and attention to the particularity of the represented. Through relations of care, dependents can continually work with dependency workers to experiment with and design new forms of responsiveness, by paying attention to the particularity of their fluctuating bodies and health conditions. The dependency worker's access to such information of the dependent's competencies and the forms

of responsiveness the dependent establishes through his interactions with the dependency worker, as developed out of a context of precarity, are both vehicles through which dependents can exercise an on-going influence on relations of authorization and accountability in medical bureaucracies and institutions of care. Such a shared perspective, looking out from a relation of dependency, when mobilized in the process of representation, paves way for the empowerment of the dependent because it increases not only his self-esteem as an individual, but also, the performance of institutions of care--shielding dependents from the differential distribution of precarity.

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