

The institute of Leslie Swartz: An ethics of care story



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Setting the world to rights

Barely out of clinical psychologist training a second career ago, a naïve 'someone should do something!' grew stronger the longer I worked in public health intellectual disability services. The deep injustices in South Africa's unsettling approach to intellectual disability care fuelled a discomfort that would lead to doctoral research with Leslie's guidance (Capri 2016). At the time, I had no knowledge of critical studies, care ethics, or disability models, but I knew something was wrong. Still unsure but bolstered by Valerie Sinason (2010), I drafted a bold proposal that I believed would set the world to rights. The send button was pressed, unknowingly setting in motion the next 15 years of a professional journey as the words landed in The Disability Guy's inbox.

And he responded.

Kill your darlings

Invited to sit around *that* kitchen table for a first meeting, Leslie took my vastly overambitious plan, sat me down with the work of Joan Tronto and Eva Kittay and an attainable idea took shape. His first piece of advice would reign in my writing over the next 3 years: talk simple. Kill off your darlings. Do so ruthlessly. I left armed with readings, homework and so many questions, but was invited back. From that point on, we sat together every 2 weeks, and each time Leslie was prepared as if our work had been his only focus.

He saw what I couldn't – a chance to learn from and explore local lived experiences, the voices if you will, of intellectual disability care. From various locations on the disability continuum (Swartz et al. 2012), we wanted to amplify voices of individuals who were silenced yet had important things to say, alongside those whose protests remained unheard.

So, with Kittay represented in its pages, our layered chronicle of intellectual disability care was examined and passed by Sinason and Tronto, themselves weaved into this care narrative. The quiet awareness of having been read by such unmatched minds will last a lifetime, along with memories of presenting work with Valerie, lamenting care politics with Joan, and escorting Eva around Cape Town.

Impact factors and Leslie's impact

The *African Journal of Disability's* durability speaks to the resolute way in which Leslie can take an idea and bring it to fruition. After all, with Lieketseng Ned and Brian Watermeyer, we are celebrating him in the very journal wherein Prof. Gubela Mji conceptualised with him as founding Editor-in-Chief almost two decades ago.

Leslie's acknowledgement and respect for collaborators leaves a mark on his students and colleagues as we continue to do the same for one another. My collaborations with Leslie and others are captured in writings on Esidimeni (Capri et al. 2018), barriers to implementing National Institute for Health and Care Excellence (NICE) guidelines (Coetzee et al. 2019), intellectual disability rights (Capri et al. 2018), psychiatric nurses' experiences of intellectual disability care (Capri & Buckle 2015), and the unethicity of excluding intellectually impaired individuals from research (Capri & Coetzee 2012). They also led to articles on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as a care institution (Capri 2022), relational voluntary-assisted-advocacy (Capri & Swartz 2018a), taking an Ethics of Care lens to person-making (Capri 2018), developing an intersubjective frame for disability work (Capri 2014), and the infantilisation of adults with intellectual disability (Capri & Swartz 2018b).

Note: The manuscript is a contribution to the themed collection titled 'Growing disability studies on the African continent: The career contribution of Prof. Leslie Swartz' under the expert guidance of guest editors Prof. Brian Watermeyer and Prof. Lieketseng Ned.

Under the supervision of Leslie, a developing confidence in intellectual disability scholarship blended with boots-on-the-ground clinical psychology practice – implementation of findings and new learning is something he always conceptualises as an outcome of research. For example, *that introduction* to Ethics of Care in Leslie's kitchen became a 2021 position article with Ockert Coetzee on harsh caregiving, abuse and neglect, and the need for transformation in public mental health settings for individuals living with intellectual disability. Our objectives were two-fold: to disseminate information and escalate our concerns regarding restrictive care practices to decision-makers in government and to make a professional contribution to their plans for overhauling mental health and residential services in the Western Cape.

Working with Leslie also became an illustration of how academic research can be directed into practice to drive positive change while tackling clinical needs in resource-stretched public health services: from developing group psychotherapies with men with intellectual disability and addressing urgent cases of unsafe behaviours and risk, to establishing an outpatient multidisciplinary therapy and assessment room for young children with intellectual and developmental disabilities. Leslie's commitment to integrating research and practice left a lasting impact.

Leslie's ethics of care

Leslie's distinguished career as a clinical psychologist, his contributions to disability studies and his academic generosity woven into our Ethics of Care story can be further celebrated through the lenses of Tronto's and Kittay's frameworks. In doing so, we see how his careful work advanced critical psychology and disability studies while embodying a transformative, inclusive, and essentially democratic care ethic.

Leslie's fold of thinkers is clear testament to his profound impact on critical and disability studies. His seminal contributions that weave together rigorous scholarship with the lived realities of disability, thereby illuminating the intersections of power, identity, and care concur with Tronto's (2011) relational and political view of care. She argues that care is not only about meeting immediate personal needs, but a fundamentally political and public resource. While Leslie's work underscores Kittay's recognition of dependency and the importance of communal care and interdependence as a normal part of human life (Swartz 2011, 2012a, 2012b), his fostering of inclusive academic spaces and reshaping of institutional power structures highlights Tronto's political approach to care as a communal resource that requires respectful, thoughtful, and fair distribution. With researchers such as Lieketseng Ned, Johannah Keikelame, Kudakwashe Dube and Hisayo Katsui, Leslie would go on to encourage African notions of interdependence when addressing knowledge gaps about how care is constructed in the Global South (Katsui & Swartz 2021; Keikelame & Swartz 2019; Ned, Dube & Swartz 2022; Ned, Keikelame & Swartz 2022).

In the ongoing aftermath of 2018's Esidimeni disaster, Tronto's (2013) *caring with* took on an especially personal meaning. Her emphasis on solidarity, trust, and collective responsibility – care fundamentals so clearly lost in Esidimeni – reminds me of collaborating with Leslie on how the distribution of reimagined care in intellectual disability spaces could begin.

Of the many things that set Leslie apart, one must be the mutuality with which he shares academic relationships curated and consolidated over many decades. Leslie brings Kittay's (2019) reciprocity to life not only in his academic generosity but also in *Able-Bodied: Scenes from a curious life* (2010). In *Able-Bodied*, Leslie's narrative of interdependence as a central facet of human life – an important part of a shared social fabric – gives character to Kittay's (2011a) norm of dependency (Keikelame & Swartz 2018). For both Kittay and Swartz, dependency is not simply a state one dips in and out of at various times and to various degrees. Rather, the looming inevitability of being dependent on other human beings is an inherent condition of the human state. Because we are equal in our inescapable dependence, this state is reciprocal. Such reciprocity renders our latent interdependence into a source of equality in our mutual need for support, and thus a source of dignity and worth (Kittay 2001; Kittay, Jennings & Wasunna 2005). We only need to turn to *How I Lost My Mother: A story of life, care and dying* (Swartz 2021) to see how Leslie's work upends dominant narratives on ability, dignity, and worth. *How I Lost My Mother's* deeply personal care experiences challenge traditionally private care boundaries. It persuades us to view disability as a vital expression – not limitation – of human diversity that enriches our shared experience and deepens our understanding of equity in our inevitable interdependence (Kittay 2015b).

Tronto (2013) would encourage us to view Leslie's interrogation of care and ableism as part of a broader project – one that challenges and transforms dominant discourses by centring narratives of care around the lived experiences of marginalised groups. His approach to academic supervision, clinical training, and critical writing insists that care is not merely invisible work performed in private domains, but rather a political practice that brings power relations into public scrutiny to be reassembled and equalised.

In levelling out such hierarchies, Tronto's (2013) concept of *caring with* equally applies to Leslie's academic practice. His willingness and commitment to sharing his expertise (and the experts in his network built over decades), mentoring colleagues, and fostering inclusive scholarly communities embodies Tronto's political and collective dimensions of care. By continually calling dominant narratives into question, Leslie commits to a reconceptualisation of 'who gets to decide what counts as legitimate knowledge', and, perhaps more importantly, *whose* knowledge is deemed more legitimate. He encourages us to surrender to epistemic humility, to a truer expertise located in stories of lived marginalisation, exclusion, and disablement (Kittay 2020).

This reclaiming of knowledge, grounded in lived experiences alongside robust examinations by scholars from diverse backgrounds, some with disabilities themselves, aligns with Tronto's (2020) democratisation of care.

Leslie's research and advocacy have sought to dismantle stigma and promote policies that recognise the value of every individual, regardless of 'bodiedness' or where they happen to be located on the continuum of 'changing states of impairment and health' (Swartz et al. 2012:951). While Kittay's (2011a, 2019; Kittay et al. 2005) focus on dependency and inclusion is particularly relevant to disability studies, Swartz's work reframes disability not as a mark of diminished worth but rather as an attribute of human diversity. Disability, then, is deserving of care and a humble recognition that we share common vulnerabilities of blood, brain, and bone.

Kittay would argue that justice requires reforming our social and institutional policies to better accommodate and celebrate human vulnerability. By reading Kittay (2011b, 2015a, 2015b), we see that Swartz provides a framework for reorganising both academic priorities and societal norms, helping to shift a narrative of deficiency to one of mutual interdependence and vulnerability, and enriching moral and political discourses on care justice. By advocating for the rights and dignity of people with disabilities, and by challenging traditional paradigms that overvalue able-bodiedness above all else, Swartz and Kittay converge on the intention to centre ethical and political transformation around the universal human condition of *ubuntu* – 'an African ethic of interdependence and relatedness' – and inherent dependency (Keikelame & Swartz 2018; Mpoe & Swartz 2019:4). Consistent with Kittay's (1998, 2025) call for policies that support those who supply the care we demand but are unable or unwilling to provide, Swartz lays the bedrock for work to be taken forward on crafting a more equitable society in which we will all eventually become care dependent. The ideological concept of *ubuntu*, literally 'humanness', adds much to this by enriching their care ethic with an African idea of mutuality, whereby 'one's humanness is instantiated through one's caring for others' (Smith et al. 2013:498). Framed by the care ethic of *ubuntu*, 'the doing' of care work in society – no matter the setting – is then valued as purposeful and with respectful acknowledgement to all participants involved in the exchange of care labour.

Yet Leslie's work engenders a disquietude about the interplay between disability, inequity, and the distribution of care resources and the impact of their rightful distribution – or loss – across policy, funding, and programme settings (McKinney et al. 2024; Mkabile & Swartz 2022; Swartz 2019; Swartz & Bantjes 2016; Swartz & Schneider 2006; Watermeyer & Swartz 2008). Irrespective of the fact that this redistribution has always mattered and we have been caring, we must care now more than ever.

We learn from Kittay (2011b, 2015a, 2015b) that justice for dependency care, and for those individuals who exchange it, requires the nurturing and safeguarding of socio-political

policies by weaving human vulnerability into the fabric of caring societies. As constitutional government and hard-earned inclusion, equity, and diversity projects come under threat in a rights-sensitive part of the world (Trotta, Shalal & Flowers 2025), we risk overlooking creeping indifference to the relegation of disability issues in less clamorous countries.

Such injustice should scare and unsettle us all.

It matters when the moral worth of people 'who cannot be self-reliant, autonomous, or productive in the ways that are commonly valued' is being rescinded (Kittay et al. 2005:456). It matters when their places 'at the table where their fates may be decided' are taken away (Kittay 2009:620). I do not have the courage to play out scenarios in which an expunction of human worthiness, value of life, equal rights, and equitable access to socio-political citizenship becomes increasingly real and deletes our interdependent humanity. But Leslie has shaped others who might, and who will. A next wave of subversion is required – one that reshapes possibilities for disability, care, and social justice (Swartz et al. 2012). Because when the human condition is being challenged, it 'matters that others take up the scribe function' (Sinason 2010:3).

An ethic of other-centredness

Beyond his humaneness and scholarly achievements, Leslie embodies a range of qualities that have either endeared him to, or distanced him from, those who know him: persistence, generosity, humour, adamance, vulnerability, brilliance, wisdom, defiance, vigour, and a willingness to embrace the new and never-been-done. His eclectic reading habits enrich conversations that would, from time to time, include references to *You Magazine*, blending the serious and whimsical in ways that only Leslie can. As supervisees, mentees, colleagues, or friends, we have all gathered around *that* kitchen table for meaningful discussions, and have left feeling valued and heard, even amid the half-dozen other appointments Leslie had that day. A bit later in the week, perhaps having gone out for milk, you realise how intently he focussed on you, and how he guided you through complex arguments while gently steering you away from potential pitfalls.

Leslie's mentorship is a delicate balance of support and autonomy, of calm disagreement with your ideas while steeling you for bold risk taking. His belief in others' potential has encouraged the development of numerous individuals into authentic practitioners and rigorous academics. His inimitable legacy, both personal and in print, will continue to invigorate the work of colleagues and inspire future scholars for generations to come. Beyond advancing academic discourse, his influence extends into the personal and professional journeys of many. Beyond his research output and pioneering ideas, Leslie is *in* the lives he has touched, minds he has inspired, and the enduring academic community he has helped to shape.

As we celebrate his incredible contributions, let us wish him health, rest (in whatever form it may come), contentment, and peace, and let us do so with care.

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