

Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

The Right to Be Freepeople: Relational Voluntary-Assisted-Advocacy as a Psychological and Ethical Resource for Decolonizing Intellectual Disability

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Abstract

Participating in social activism implies responsibility for its exchange and creation. We focus on Intellectual Disability (ID) as an advocacy site for individuals who are dependent on assistance with activities of daily life, and attend to the process of taking care during social justice projects. Our paper responds to current South African social justice controversies perpetrated against people who may be unable to independently mobilize against increasingly othering – even deadly – socio-political conditions. Underpinned by relational Ethics of Care, voluntary-assisted-advocacy can be a psychologically relational, intersubjective, and societal project that strives for ID citizenship-making and social justice. This paper draws on numerous interviews and a number of ethnographic observations in exploration of ID care. Empirical material was subjected to thematic content analysis, and participant quotes bring our argument to life. Relationships among people with Intellectual Disability (PWID) and non-ID assistant-advocates are asymmetrical. We can either uphold dominant non-ID voices, or transform socio-political ruling relations that maintain dependence on conditions of power and inequality. Our contributions to the advocacy we co-create today will shape the activism we will depend on in the future. We consider relational voluntary-assisted-advocacy as a psychological and ethical resource for sustainable, mutually satisfying social change.

Keywords: Intellectual Disability, relational psychology, social activism, voluntary-assisted-advocacy, rights crises, South Africa

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In this paper, we grapple with the socio-political location of people with Intellectual Disability (PWID)ⁱ in a country in the Global South. PWID are equally dependent, if not more so than others, on scarce public resources, but the direction of policy decisions and distribution of appropriate services rarely occurs in their favor (McKenzie, McConkey, & Adnams, 2013). PWID in South Africa are confronting socio-political changes that affect their lives, but have little to no opportunity to give input (Capri, Watermeyer, McKenzie, & Coetzee, 2017).

In what is now known as the Esidimeni crisis, 140 South Africans, most of them PWID, died after being moved from state-supported care to inadequate and, indeed, fatal care arrangements (Capri, Watermeyer, McKenzie, & Coetzee, 2018). The lethal treatment of care dependent people begs for changing those conditions which perpetuate social injustice and deprecating health. Our ideas regarding *voluntary-assisted-advocacy* emanate from our feelings about such injustices against PWID. We turn to some examples as background to our study. As the paper's authors, and members of broader disability advocacy, we illustrate with examples from our own experiences and introduce the dilemma that drives our argument: do we advocate for people who are assumed unable to do so, but risk upholding dominant voices, or do we withdraw assistance so as to not colonize and contaminate ID issues with non-ID voices?

Voluntary-Assisted-Advocacy

Advocacy by dominant, non-ID voices could disempower PWID by perpetuating “only what other people [want]” (Clegg, 2006, p. 131). In this discussion we introduce our notion of voluntary-assisted-advocacy, an approach which, if defined at its core, holds the principle that PWID drive social change agendas in relationship with non-ID assistant-advocates. Once a social justice claim has been identified, the principle that PWID approve ideas that reflect their experiences, and “reject those that do not”, is central to voluntary-assisted-advocacy relationships (Clegg, 2006, p. 131). Voluntary-assisted-advocacy is egalitarian, recognizes that a truer ID expertise is held by PWID than by non-ID activists, and espouses respect for the specific needs of PWID who set the kinds and levels of assistance needed. Equitable support requirements during advocacy activities will exceed minimal levels but are still provided – whether assistance is accepted remains an individual's choice and is the point of voluntary-assisted-advocacy.

We will talk about how voluntary-assisted-advocacy engages with disability scholarship by drawing from Tronto and Kittay's Ethics of Care principles. By intersecting activism and research, voluntary-assisted-advocacy might be useful for informing research and policy, foregrounding self-identified life requirements, designing services and care practices, lobbying for ID citizenship and rights implementation, developing political behavior, realizing socio-economic participation, and facilitating engagement among PWID and assistant-advocates who wish to change restrictive socio-political conditions.

In order to further conceptualize voluntary-assisted-advocacy, we offer some examples where it could be of relevance, interrogate our ensuing dilemma and pull out its resultant questions. Although the issues raised might be equally relevant to PWID in countries that train ID physicians (the Netherlands) and ID psychiatrists (the United Kingdom), we draw on South African examples and quotes from our research participants. Some related implications for voluntary-assisted-advocacy bring our discussion to a close.

Background

Most individuals with disabilities live in the Global South, representing nearly one quarter of the world's poorest people (Emerson, 2007; Groce, Kumbhavi, et al., 2011; Groce, Kett, et al., 2011). Approximately 200 million people live with ID, making it the world's most prevalent disability (World Health Organization & World Bank, 2011). With less expectation of competence but of increased problems, PWID are more often unemployed or underemployed compared to the general population and other disability groups (Carvalho-Freitas & Stathi, 2017). Socio-political exclusion, isolation, segregation, abuse, neglect, stigma, and death have resulted from ignorance,

fear, misconceptions, and discrimination regarding PWID (Byrne, 2018; Flores, 2017; Maclean et al., 2017; Makgoba, 2016; Wissink, van Vugt, Smits, Moonen, & Stams, 2018).

Frequently violated rights of PWID in private and public settings pertain to sexual and physical abuse; problems accessing services; involuntary institutionalization; denial of consensual sexuality, marriage or parenting; exploitation; unemployment and occupational restrictions (De Vries, Venter, Jacklin, & Oliver, 2013; Drew et al., 2011; Roy, Roy, & Roy, 2012).

Despite ratifying the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) a decade ago (United Nations [UN], 2007), South Africa's legal system has yet to assimilate the international conventions into domestic legislation on behalf of PWID (Huus, Granlund, Bornman, & Lygnegård, 2015). South Africans with ID, however, are entitled to social justice as equal citizens (Republic of South Africa [RSA], 1996). Yet PWID are often at risk of lifelong dependence on caregivers, a relatively powerless societal position (Calitz, 2011; Reeve, 2006), and have little access to resources. Relative to levels of functioning (see Figure 1), some individuals with ID can resist subordination, practice self-determination, participate autonomously, and exercise their potential with less assistance. Voluntary-assisted-advocacy can support self-advocacy, but would only occur if asked for and in adherence to the requirements and requests of the person with ID. While individuals with Mild ID might be more able to self-advocate, people living with more severe levels of ID would be less likely to do so unaided.

Parallels exist between politics of voice in the Global South and access to voice by PWID, broadly defined to include non-verbal PWID who also have something to say. As with conditional aid arrangements between the Global North and South, little space is left for PWID to negotiate power when their every support requirement depends on others' socio-political practices. Given the direction of power in asymmetrical relationships, protest by PWID is readily viewed as a hindrance and "likely to be taken as resistance or obstruction" (Tronto, 2010, p. 165). Efforts at behavioral self-representation can be dangerous when powerful assistants attribute this means of protest as aggression and behaviors that challenge. Similarly, resistance from the Global South to conform to aid conditions can result in withheld benefits as a form of political pressure to comply.

The following examples highlight a lack of consultation with PWID, lend context to the questions we ask in light of our dilemma, and illustrate how discriminatory policies can impact the lives of PWID when denied "a place at the table where their fates may be decided" (Kittay, 2009, p. 620). Excluding PWID from decision-making processes that can cost their lives is unjust (Kittay, 2009). The Esidimeni disaster evinces ignorance of non-derogable rights violations that make it hard for PWID to be alive. It also reveals consequences of disregarding advice.

Fatal Care: Esidimeni

An arbitration into the most catastrophic care disaster in South African recorded history heard closing arguments on Friday, 9 February 2018 (Nicolson, 2018). Although the Gauteng (province of South Africa) Director of Mental Health Services was warned in 2015 that community care for deinstitutionalized PWID was lacking, the "Gauteng Mental Health Marathon Project" continued into 2016 and 2017 for disputably financial reasons (Makgoba, 2016, p. 1; Rahlaga, 2018).

By June 2016, 2 267 people had been transferred from Life Healthcare Esidimeni facilities to community based non-governmental organizations. Three months later, the National Health Minister initiated inquests into mounting deaths of former Esidimeni residents (eNews Channel Africa, 2018). A Health Ombud report was released on 11

February 2017. Arbitration began in October 2017 chaired by former Deputy Chief Justice Dikgang Moseneke (African News Agency, 2017).

At least half of the deceased lived with high support needs and severe to profound ID, and died from cold, hunger, dehydration, and infection (Capri et al., 2017; Makgoba, 2016). At the time of writing, 140 people have died while more than 50 remain unaccounted for (Chabalala & Pijoos, 2018). The dead cannot speak, but Esidimeni victims who are still suffering have as little voice. Clinicians, families, and officials were called to testify at the hearings, but no PWID were heard (J. McKenzie, personal communication, 2018). Makgoba's (2016) Ombud report equally lacked testimony from PWID.

PWID Do not Count

State counsel argued that Esidimeni victims are not entitled to constitutional damages and that evidence of non-derogable rights violations must be ignored (Bornman, 2018). Although a formally dismantled political project, *apartheid* is seemingly perpetuated in human worth politics. South Africa's 2001 National Census excluded PWID in institutional care, effectively remanding them to non-entities. Despite exceeding ID rates in high-income countries, South Africa's last accurate prevalence studies date to the 1990s (Christianson et al., 2002; Kromberg, Christianson, & Manga, 1997; Kromberg et al., 2008).

Furthermore, "[i]ntellectual disability was not measured directly" during the 2011 Census either, while (very) young children with disabilities were not profiled at all (Statistics South Africa [SSA], 2014, p. 23). Although SSA (2014) is aware that persons with severe disabilities tend to live in care facilities, PWID in such settings were again excluded from the 2011 count. Applying the Washington Group Short Set of Disability Questions to South Africans with "difficulty remembering or concentrating" was the closest inclusion criteria for ID (SSA, 2014, p. 34; Washington Group on Disability Statistics, 2018).

South Africans With ID: No Person No Vote

Citizenship encapsulates rightful participation in national spaces while duties and obligations toward others are upheld (Yeung, Passmore, & Packer, 2008). Although South Africa's political rights enfranchise prisoners (Constitutional Court of South Africa, 1999; s19.3a, RSA, 1996; Swart, 2015), PWID 18 years and older may not vote freely in political contests more than two decades after the famed 1994 general election (Combrinck, 2014; Hartley, 2013; Ndenze, 2013; RSA, 1998a). An outmoded "unsound mind" aphorism still justifies disenfranchisement regardless of constitutional citizenship (s8.2c, s20, RSA, 1996), international support (Article 29a, UN, 2007; Combrinck, 2014) and suffrage elsewhere (Hood, 2014; Kjellberg & Hemmingsson, 2013; The Electoral Commission UK, 2015).

By ratifying the UNCRPD (UN, 2007), South Africa committed to championing the human rights of PWID (Officer & Shakespeare, 2013). A decade later, lawmakers' ongoing lack of political will to understand what "intellectual disabilities actually *mean*" surely constitutes a political injustice (emphasis added) (Government Gazette, 2015, p. 50).

Multi-Layered Socio-Political Injustices

When combined with poverty, lack of government services integration to meet basic needs of PWID creates dire living conditions (Saloojee, Phohole, Saloojee, & IJsselmuiden, 2007). Graduates from various disciplines are ill-prepared for meeting ID service needs (Geiger, 2012; Roberts, Chetty, Kimmie-Dhansay, Fieggen, & Stephen,

2016), but ID expertise is predominantly located in non-ID individuals at tertiary institutions from which PWID remain excluded.

Although there is South African literature on justice for PWID who are crime victims, three studies published during the past 25 years barely touch on offenders with ID (Capri, Abrahams, et al., 2018). Without assistance and consideration of their specific needs, offenders with ID face obstacles to procedural justice. They enter a criminal justice system where even non-ID individuals find rules, processes and procedures difficult to understand. Testifying to their own case, fair treatment and equality before the law becomes problematic for PWID.

Selecting a Theoretical Frame for the Work

Our Dilemma

When PWID with high support needs are mistreated, the temptation to advocate increases, especially when political responses are tepid (Mahlase, 2018; Masweneng, 2018a, 2018b). There has to be a way of resolving the dilemma of either withdrawing under the guise of fostering independence (while Esidimeni unfolds in the press); and working toward social justice in a dignifying and collaborative way (Capri et al., 2017; Swartz & Marchetti-Mercer, 2018). “Giving” voice to people who may be unable to independently mobilize against injustices becomes problematic – we silence them while paradoxically reproducing dangerous stereotypes of PWID who cannot express their grievances for themselves (Capri et al., 2017; Swartz & Marchetti-Mercer, 2018).

While it matters that we act for “people who cannot think, remember, speak, or write” (Sinason, 2010, p. 3), and that we articulate the worth of individuals who cannot contribute in commonly valued ways (Kittay, Jennings, & Wasunna, 2005, p. 456), it is also maintained that traditional knowledge hegemonies have marginalized “the most important voices ... in discourses on disability” (Capri & Coetzee, 2012, p. 2). As ID activists, we can battle perceived injustice but run the risk of imposing our hegemonic narrative on non-dominant voices. Our power to speak on behalf of PWID can limit inclusive spaces for ownership of the conversation (Capri et al., 2017).

Since inaction is a counter-productive and unlikely option, relational advocacy as a form of social activism can be one way of interrogating our dilemma. Transforming unhelpful socio-political attitudes toward marginalized individuals requires mutually satisfying critical engagement with oppressive structures we comply with and ableist practices we collude with (like speaking-*for*-advocacy).

During any given work day, we deal with issues that speak to the predicament of using our agency and inadvertently disabling PWIDs’ use of voice. While the above examples complicate our project of voluntary-assisted-advocacy, they elicit questions pertinent to our discussion:

1. If appropriate representation is absent, would a victory in the above examples be empowering (Swartz & Marchetti-Mercer, 2018)?
2. We can encourage PWID to make justice claims for supposedly guaranteed protections and resources (Kittay, 2009, p. 624), but how are people, less able to self-advocate without assistance, to make these initial claims?
3. How can PWID influence their own fates if disability activists occupy advocacy spaces in their stead?

4. If we reproduce patronizing advocacy by colonizing ID voices (Child, 2017; Swartz & Marchetti-Mercer, 2018), is it still “politically correct” to advocate on behalf of PWID? Should we not rather stay silent in order to avoid the politically offensive practice of colonizing ID issues?
5. Not positioned as post-liberal citizens or consumers of the capitalist complex (Tronto, 1993, 2010), PWID are kept out of mind as non-productive individuals who, in their consumption of our labor, do not deserve to protest. Can PWID rightfully engage in dissent on condition that they turn into producers who may complain if something does not suit?
6. If one cannot express disagreement verbally, or if you can but are not heard, how do you protest? Where do you turn if you need to inconvenience the agenda of powerful assistants?
7. Can we honor PWID by increasing interpersonal compensation and reassurance in a collaborative way *because* individual powers have failed (Morris, 2001)?
8. Can we decolonize the voices of PWID by taking a speaking-*with* position that dilutes non-ID dominant narratives (Swartz & Marchetti-Mercer, 2018)?

We believe ID voices must contribute to the reorganization of dominant political complexes.ⁱⁱ But because we cannot know what a person with ID might need, since (a) we do not have ID, and (b) every person with ID has particular needs (Tronto, 2010), we also believe that PWID should self-determine the targets for change and assistance required, as far as possible (see Figure 1). Since the interests of PWID are preferenced, our assistance can be requested once an individual identifies a life quality claim and enlists our help to think about what needs to be said and done (Capri & Coetzee, 2012; Walmsley, 2014).

Our notion of relationship among PWID and non-ID assistant-advocates engages with disability scholarship and draws from Tronto and Kittay’s Ethics of Care principles. When applied to issues of ID citizenship and policy creation, the former speaks to socio-political participation as freepeople and the latter to the ethical collection and value of insider narratives for understanding ID issues.

Ethics of Care Theory and Human Interdependence

Generally, Ethics of Care is a normative theory that questions justice and injustice, and does so by drawing attention to how we respond to people who are vulnerable to our choices and depend on our care – especially if “[w]e human beings are the sorts of beings we are because we are cared for by other human beings” (Kittay, 2009, p. 625).

More specifically, Tronto (2010) and Kittay (2009) suggest that human life is relational, that we are not isolated selves, and that we exchange care in every relationship. Dependence and interdependency are central to being human, and individualist human independence is interrogated. We cannot survive without assistance in times of vulnerability and need. Care is provided when required, and we strive to eliminate barriers that constrict “freedom to exercise whatever capacities one has or can develop” (Kittay et al., 2005, p. 458). Whereas a just society would meet needs within the constraints of available resources, it can be disabling when constraints are cited as an excuse for *not* meeting needs in ways that contribute to developing capacities across various adaptive domains.

Kittay et al. (2005) do not view needing assistance as a limitation, but as a social resource. If commonplace, assistance secures relationships in which having unequal support needs is safe. If assistance is not withheld, regardless of required support level, it becomes equally safe to need more or less support. Ethics of Care promotes dignity of dependence since we are moral equals in our inevitable need for care. PWID are not obliged to accept

inappropriate care, and may refuse assistance that makes them feel bad. Care ethicists value human variation that is not contingent on independence. Value is found in needing one another, and dignity does not require reciprocal exchanges in symmetrical relationships of power (Kittay, 2009).

Humans' continuous and inevitable need for assistance implies interdependence, celebrates others' support of dependents whom we are unwilling or unable to assist ourselves, and emphasizes that the individuals who care for others (and thus also for us) be justly cared for in turn (Tronto, 2010).

From an Ethics of Care perspective, disability advocacy should examine its purpose, recognize power relations among PWID and non-ID assistant-advocates, and meet individuals' social justice ends by means of particular assistance. ID activism is not over once we believe a protest has been executed successfully (Tronto, 2010), but completed and legitimate only if accepted by PWID (Kittay, 2014).

Engaging in mutually satisfying activism now, in the form of relational voluntary-assisted-advocacy, can help create a care-interdependent society in which we need not feel bad about our selves when we become unable to advocate for ourselves.

Method

Positionality of the Authors

The terms “we”, “our”, and “us” include other willing disability rights advocates and locate our voices as the authors. As does the Bill of Rights (RSA, 1996), we believe PWID should be equally enabled to not only claim social justice, but receive its subsequent resources and protections (Kittay, 2009, p. 624). We both are clinician-researchers and licensed psychologists in South Africa, perhaps the most unequal society in the world (World Bank, 2017), and one of us works in public ID mental health care facilities. Our key performance areas include advocacy and community engagement. Our experiences of studying institutionalized psychiatric ID care (Capri, 2016), together with Esidimeni and its aftermath, play the biggest role in wanting to change deteriorating political relations and social conditions pertaining to PWID.

Working in the field of ID as able-bodied and non-ID is not uncomplicated (Capri & Swartz, 2018; Swartz, 2010), as is being occupational specific professionals in the Global South who earn a relatively good South African wage. We consider ourselves well-meaning when we point to performances of racism as White people, and when we write about the injustices of infantilization on behalf of PWID. In both instances, voice and expertise is located in the wrong place, and authenticity – the issues that *really* matter but we have no awareness of because we are not Black nor do we live with ID – is lost. This brings us back to our dilemma: contingent on level of severity of ID, there are people who are not as able to make justice claims for resources and protections as ID self-advocates are. But is advocating on behalf of PWID presumably unable to self-advocate an appropriate form of engagement, does it serve the ID community, is it socially just, and can it help society welcome PWID?

The examples of how PWID are treated and responded to in South Africa highlight areas in which voluntary-assisted-advocacy, alongside self-advocacy, can enable action for social justice. They also identify ongoing issues that we can collaborate on with self-advocates in order to inform appropriate policy within a broader Ethics of Care frame.

Data Collection

Our thoughts regarding voluntary-assisted-advocacy stem from exploring ID care performance with PWID who live with mental ill-health in psychiatric settings, interviewing their non-ID assistants, and collecting ethnographic data on inpatient wards (see Table 1). We gathered data from three sources within two separately functioning South African specialized ID care sites. Information of participants with ID (see Table 2) includes terminology per the Employment Equity Act (RSA, 1998b). Descriptors that would have rendered participants of this racially diverse group identifiable were excluded.

Table 1

Qualitative Research Methodology and Data Collection

| Research method | Participants | Data collection | Data capturing | Data treatment | Data analysis |
|-----------------|--------------|---|--|--|---|
| A. Ethnography | Wards | <ul style="list-style-type: none"> Care participant observation 3 wards 45 hours | <ul style="list-style-type: none"> Field journal | <ul style="list-style-type: none"> Interpreting field notes Triangulating with B and C | Observational data were examined and interpreted for common themes |
| B. Narrative | Nurses | <ul style="list-style-type: none"> Free Association Narrative Interviews 16 nurse participants 14.9 hours | <ul style="list-style-type: none"> Digital voice recorder Research journal | <ul style="list-style-type: none"> Transcription Triangulating with A and C | Narrative data were examined and interpreted for common themes until saturation reached |
| C. Narrative | Residents | <ul style="list-style-type: none"> Intersubjectivity informed therapeutic interactions 10 resident participants 59 hours | <ul style="list-style-type: none"> Digital voice recorder Research journal | <ul style="list-style-type: none"> Transcription Triangulating with A and B | Narrative data were examined and interpreted for common themes until saturation reached |

Table 2

Resident Participants' Demographics

| Participant | Gender | Race | Research site | Level of ID | Interview language | Consent or assent |
|-------------|--------|---------|---------------|-------------|-----------------------|-------------------|
| Resident J | Male | White | 2 | Mild | Afrikaans | Consent |
| Resident J2 | Female | Colored | 1 | Moderate | Afrikaans | Assent |
| Resident N | Male | White | 2 | Mild | Afrikaans | Consent |
| Resident E | Female | White | 2 | Moderate | Afrikaans | Consent |
| Resident G | Male | Colored | 1 | Moderate | Afrikaans and English | Declined |
| Resident R | Male | Colored | 1 | Severe | Afrikaans | Assent |
| Resident W | Male | Colored | 2 | Mild | English | Consent |
| Resident T | Male | White | 2 | Moderate | Afrikaans | Consent |
| Resident G2 | Male | White | 2 | Moderate | English | Declined |
| Resident D | Female | White | 2 | Mild | English | Consent |

The impairments PWID live with are no longer considered fixed and categorical but move along a continuum of domains that inform on severity level of ID. Impairments are likely not reversible and assistance needs will vary according to required levels of support, but individuals can be aided in developing adaptive skills to overcome particular limitations.

| <p>Level of ID</p> <p>Support requirements</p> | INTELLECTUAL FUNCTIONS | ADAPTIVE FUNCTIONING | | |
|---|---|--|---|--|
| | <p>Conceptual Domain</p> <ul style="list-style-type: none"> • How the individual uses reasoning, problem solving, planning, abstract thinking, judgement, learning from experience, and learning in educational settings • How the individual uses time, money, the telephone, and technology devices | <p>Socialization Domain</p> <ul style="list-style-type: none"> • How the individual <ul style="list-style-type: none"> ◦ uses job skills (community) ◦ interacts with others (interpersonal relationships) ◦ uses leisure time ◦ demonstrates responsibility and sensitivity to others (coping skills) | <p>Communication Domain</p> <ul style="list-style-type: none"> • How the individual listens and pays attention, and what he/she understands (receptive) • What the individual <ul style="list-style-type: none"> ◦ says, how he/she uses words and sentences to gather and provide information (expressive) ◦ understands about how letters make words, and what he or she reads or writes (written) | <p>Daily Living Skills Domain</p> <ul style="list-style-type: none"> • How the individual eats, dresses, and practices personal hygiene (personal) • What household tasks the individual performs (domestic) |
| <p>Level of ID</p> <p>Intellectual and adaptive functioning</p> | Level of Intellectual Disability | | | |
| | Mild Intellectual Disability | Moderate Intellectual Disability | Severe Intellectual Disability | Profound Intellectual Disability |
| | <ul style="list-style-type: none"> • Support is needed in one or more areas to meet age-related expectations • Few barriers to social inclusion | <ul style="list-style-type: none"> • Ongoing and generalized assistance is required on a daily basis to complete conceptual tasks of daily life • Care givers assist person with life decisions | <ul style="list-style-type: none"> • Care givers provide extensive supports with all activities of daily living and problem solving throughout life • Individual requires supervision at all times | <ul style="list-style-type: none"> • Individual is dependent on others for all aspects of daily physical care, but might be able to participate in some of these activities • Co-occurring physical and sensory difficulties are frequent barriers to participation and social inclusion |

Figure 1. Continuum of support needs according to severity of ID^a.

^aAdapted from: APA. (2013). Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5.

Findings

ID Activism by Means of Relational Voluntary-Assisted-Advocacy?

Ethics of Care theory implies that a traditionally dependent person can drive, request, reject, accept, suggest, or modify activities and relationships with non-ID assistants. By involving PWID directly in their own treatment, change could be initiated in ableist institutional systems. During our research, Resident J enquired about assistance with behaviors that challenge and whether his self-determined transfer request was discussed with a self-identified audience:

RJ: So did you tell [clinician M] what I said?...I'll get out of here. (Resident J)

CC: How?

RJ: They'll talk about my behavior and manners. The nurses. The staff.

CC: What will they say?

RJ: They'll say, "No, let him go back, you might as well. He was nicely behaved and his manners were nice. He wasn't rude".

Accounting for interdependence, relational voluntary-assisted-advocacy focuses on (a) assisting PWID now, and (b) assisting our future selves while doing so. We are contributing to the kind of society and assistants we want for ourselves when we become increasingly dependent in *that* society on *those* assistants. We are culpable in

shaping the society we will be vulnerable in, policies that will enable or disable us, and assistants that will co-create our care with us.

Relational voluntary-assisted-advocacy asks us to reflect on the kinds of people we make during activism performances by challenging our contributions to the disablement of those who, for now, depend on us. Because it lets us relinquish power imbalances that suspend the voices and agendas of PWID (Lynggaard, 2008), we can admit to our non-expertise in living with ID without needing to shame people for their vulnerability or hold power over them. Given dominant neo-liberal societal power relations, socio-political inclusion similarly depends on the ways in which non-ID politicians, as fellow person-makers, practice inclusion.

Co-Creating Socio-Political Citizens

As do we all, PWID use others' minds to gain knowledge about themselves (Fonagy & Target, 2007). "To know that one arouses dismay", however, "sickens the spirit of anyone" (Mairs, 1996 as cited in Morris, 2001, p. 103). PWID might internalize others' dismay as disgust for their condition (Sinason, 2010). Using non-ID researchers' findings to learn about oneself becomes the self one knows. Within a colonized mind, little space remains for self-identified research questions with which to drive socio-political change.

Intersubjectivity holds that any interaction potentially generates spaces in which interdependent people are constantly being made. In taking social action with PWID, we are essentially creating our own and others' selves. Our subjectivities – and the activism we pursue from these – are accessible for use by others as a perceived external representation of themselves, available to their inner reality as knowledge of a world that celebrates or misrepresents them. We are constantly making, and being made into, the kinds of people who produce enabled or disabled others.

In beginning to consider intellectually disabled South Africans as socio-political persons, assisting PWID with developing policy formulating and research capabilities can delineate conditions for life enhancing care and participation in citizenship (Capri, 2019; Walmsley, 2004a). Opportunities for citizenship and autonomous research might help to increase resilience against subordination and decrease subjugation dynamics.

Re-Doing Policy

A presidential report on disability did not seek input by PWID, yet claims to have used commissioned research and information from "roundtable discussions with a range of stakeholders" (Van Der Byl, 2014, p. 2).ⁱⁱⁱ When non-ID experts, perhaps in pursuit of their own agendas, differ from PWID in what is politically needed, knowledge presumed on behalf of PWID can distance them from their own experiences (Capri, 2016; Tronto, 2010, p. 163; Walmsley, 2004b) and perpetuate their unintelligent dependent status:

You must be dumb here. If you try and be clever, you'll walk into trouble. (Resident J)

In principle, relational voluntary-assisted-advocacy shifts the locus of expertise (cleverness) by holding PWID as experts on life with ID. Researchers and policy makers with ID, as contributors to political artefacts like presidential reports on disability, can inform socio-political change agendas from an empirical base (Walmsley, 2004c).

But if one's survival depends on others it might be terrifying to show dissatisfaction for dread of abandonment (Sinason, 2010). As severity of impairment increases, dependency fear of offending powerful assistants might obstruct protest. Given the positions PWID may be negotiating from, some compliance with systemic inequality

and resistance to change can be anticipated. Opposition can be costly, and care dependence might increase reticence to individuate from asymmetrical relationships (Sinason, 2010; Tronto, 2010). Ingratiating one's self to powerful assistants could remain a way of bargaining for survival:

CC: *But E, for you it feels like, only if you do something for people then they take an interest in you, and...if you don't have anything to do for them, then they go away?*

RE: *Then they don't know you. (Resident E).*

Ethics of Care principles that underpin relational voluntary-assisted-advocacy spoil such asymmetry, while claims to just treatment represent assertions of power:

RJ: *I don't know what is wrong in this place. We've reported [the problem] how many times. How's this place? Broken or working?*

CC: *You could be treated better?*

RJ: *Exactly. These things should have been fixed long ago. (Resident J)*

Eliciting Self-Identified Life Requirements

Before the policy contributions of PWID can dilute dominant non-expert voices in control of decision-making, we must "get to" expert voices of PWID with care (Capri & Coetzee, 2012, p. 956). We found that the free association narrative interview (FANI) method meets the objective of co-creating knowledge with PWID, foregrounding previously under-investigated contributions, and facilitating self-representative environments (Hollway & Jefferson, 2013).

Literature on *how* consent, assent, and particularly, refusal can take place is moving beyond issues of whether PWID can or may participate in policy informing research (Calveley, 2012; Capri & Coetzee, 2012; Kidney & McDonald, 2014; Walker, 2013):

CC: *You're looking at this [voice recorder]. Do you know it?*

RR: *Cell phone.*

CC: *Voice recorder. What you say is important. I don't want to forget. Is that ok?*

RR: *[Nods]. (Resident R, Session 1)*

CC: *Everything that we talk is private and confidential. In other words, nobody...*

RJ: *...will be told.*

CC: *Do you have any questions? (Resident J, Session 2)*

RJ: *What do you play on that thing [voice recorder]?*

CC: *I am recording so that I don't forget. Everything you say is important.*

RJ: *So where do you take that thing? And only you are going to listen?*

CC: *Because what we discuss is private.*

RJ: *Exactly. (Resident J, Session 3)*

Decision-making aids, like a protracted consent process, can assist PWID during permission processes (Capri & Coetzee, 2012). This includes viewing the decision not to participate, or to withdraw from a study after initially agreeing to participate, as indicative of a successful consent procedure:

CC: *I apologize, it's going to take me a while to learn your speech. If I don't understand you well, that's my fault, ok?*

RG: *Don't want to talk.*

CC: *That's ok. (Resident G, Session 1)*

Discussion

Implications for Voluntary-Assisted-Advocacy Practice

In considering a mutual shaping of people during interactions, advocacy is as relational an exchange as care (Kittay, 2009). Voluntary-assisted-advocacy and ID care relationships draw on this intersubjectivity precept in similar ways. If all care is relational, good or bad, and both influence the kinds of persons made during its planning and practice (Tronto, 2010), we must take cognizance of mutually exchanged and internalized subjectivities of whomever we are interacting with. But because care or advocacy is never a simple good-bad binary, we can at a minimum reject gradation among humans, foreground inclusion, emphasize mutually satisfying participation, and interrogate our hand in making enabled or disabled persons during social activism performances (Smith-Chandler & Swart, 2014; Stein & Stein, 2007). Government vows that “Esidimeni” will not be repeated (Phakgadi, 2018), but has not solicited input from PWID on avoiding such future occurrences. Voluntary-assisted-advocacy can either enable direct participation by PWID, or assistant-advocates can present recommendations from PWID.

Our ambitious idea raises questions about feasibility, implementation, and monitoring the progress of voluntary-assisted-advocacy activities. How could we go about expanding the scope of ID advocacy further? What if we start with ourselves first, then begin at work by designing the precepts of voluntary-assisted-advocacy into our supervisions, staffing budgets, Operational Protocols, and Quality Assurance documents? We can gauge attitude and disposition toward availability as an assistant-advocate on interview panels, or measure ourselves and one another against underlying principles. We could consider academic socialization, professional training modules, and research expansion. We could try and help Community Healthcare Clinics accept PWID as a matter of fact, thereby integrating services and treatment rather than “exiling” them to specialist care sites. By means of voluntary-assisted-advocacy, PWID can occupy boardroom seats and perhaps consult on future National Core Standards or Quality Standards for Healthcare. PWID and assistant-advocates could submit accessible articles based on their research, comment on draft bills, work on new legislation (like a Vulnerable Adults Act), write to newspaper editors, lobby for socio-political inclusion, participate in justice proceedings (e.g., the Esidimeni hearings), or insist that the next National Census accurately includes South Africans with ID.

Omitting PWID from censuses renders them invisible in the socio-political discourse of living with ID. We perpetuate exclusion by neglecting to question such practices (Goodley, Hughes, & Davis, 2012). If the estimated South African population is 55 908 865 (World Bank, 2017), and those with “difficulty remembering or concentrating” approximate 4.1% of the population (SSA, 2014, p. 34), there might be more than 2 000 000 South Africans with

ID. Regardless of topic, representative research samples need to include four PWID in every 100 participants. Legislators should be vying for the approval of more than one in every 25 South Africans. Assistant-activists can help lawmakers understand what ID actually means and appropriately advocate for enfranchisement (voting), suitable services (assistive technology during voting) and protections (against voter intimidation).

By excluding instructors with ID from health practitioner training programs, we lose opportunities to broaden practitioner understanding and integrate ID services (Grut, Braathen, Mji, & Ingstad, 2012). By means of fresh understanding and responses to ID, assistant-advocates can help PWID claim expertise on ID matters (Capri & Coetzee, 2012).

Concluding Thoughts

Just societies remove barriers to competency development and encourage self-determination. Relational voluntary-assisted-advocacy focuses on current and future interdependence, and on the kind of society and assistants we create for our own inevitable dependence to be cared about. ID activism for socio-political change implies advocating in a mutually satisfying way – now and for the future – with individuals who aim to support ID voices, dismantle restrictions and develop political behaviors. This also means engaging with those who prefer to uphold structural and attitudinal barriers.

Within voluntary-assisted-advocacy, emancipatory research and policy formulation can assist PWID in affecting change towards an enabling justice that tempers dangerous beliefs about ID (Clegg, 2006). If we break away from dominant voices to ultimately be led by PWID as ID experts, we might help create counter-hegemonic claims to “knowing ID”. In relational voluntary-assisted-advocacy spaces, experiences of disability are no longer bestowed upon but voiced by real experts who live with ID in a disabling world.

Notes

- i) Intellectual Disability (ID) is the clinical term used in South Africa according to the DSM-5 (APA, 2013) and equates with the term Learning Disabilities (LD) in the United Kingdom.
- ii) The terms “we”, “our”, and “us” include other willing disability rights advocates and locate our voices as authors of this paper.
- iii) The same document’s disclaimer admits to “a low prioritisation of resources for persons with intellectual disabilities” (p. 32).

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