



UNIVERSITY of
HOUSTON
GRADUATE COLLEGE
OF SOCIAL WORK



PERSPECTIVES ON SOCIAL WORK

The Journal of the Doctoral Students of the University of Houston

SUMMER 2021

VOLUME 16 ISSUE #2

Perspectives on Social Work

Editor

Caitlyn Mytelka, LMSW

Editorial Board

Gabbie Aquino-Adriatico, MSW

Anil Arora, MSW

Riya Bhatt, LMSW

Holly Davies, MSW

Priscilla Kennedy, LMSW

Ying Ma, Ph.D., MSW

Sujeeta Menon, LMSW

Lindamarie Olson, LMSW

Nikki Vogel, LMSW

External Reviewers

Bridgette Davis

University of Chicago

Jessica Curd

Indiana University

Chireau White

Adelphi University

Shivani Kaushik

Colorado State University

Melissa Murphy

Florida State University

Dylan Bellisle

University of Chicago

John Edwards

Bryn Mawr College

Haylee Hebenstreit

Stonybrook University

Crystal Garcia

*Our Lady of the Lake
University*

Fary Maldonado

University of Hawai'i

Faculty Sponsor

Susan P. Robbins, Ph.D., LCSW

Table of Contents

<u>Editorial</u>	2
<i>Caitlyn Mytelka, University of Houston</i>	
<u>How can we improve long-term equity for today's young adults? Exploring the potential advantages of a Universal Basic Income</u>	3
<i>Lara Law, Arizona State University</i>	
<u>Mobile crisis clinicians' experiences with malingering patients in acute care: A phenomenological study</u>	18
<i>April C. Bowie-Viverette, Our Lady of the Lake University</i>	
<u>Towards an intersectional intervention for LGBT people with disabilities</u>	32
<i>Rachel Womack, University of Kentucky</i>	
<u>Centering autistic persons' perspectives in autism social policy: A qualitative study</u>	47
<i>Margaret G. Janse van Rensburg, Carleton University</i>	
<u>Book Review</u>	
<u>Understanding the impact of neoliberalism and racism on the food insecure within food pantries: A book review</u>	61
<i>Jakob Mauer, Walla Walla University</i>	

EDITORIAL – Social Work Ethics in Scholarship in *Perspectives on Social Work*

Social work doctoral students bring an exciting energy to social work scholarship that strongly represents the mission of social work through research and advocacy for equitable access, services, and policies for marginalized populations and efforts to enhance wellbeing. *Perspectives on Social Work* aspires to be a platform for social work doctoral students to share their voices in critical areas of research and policy, while also serving to support students by offering opportunities to publish articles, participate in the peer review process, and network with other doctoral students. These opportunities at the doctoral level are key to developing effective social work scholars who will center the voices of vulnerable populations and work to make change and improve the field in all areas of practice. Through the tremendous efforts of *Perspectives on Social Work*'s peer reviewers, authors, and editorial board members, we will continue to offer a space for doctoral students to build connections, learn and refine skills, and share the implications of their scholarship.

This issue of *Perspectives on Social Work* features four articles and a book review that call social workers to consider inclusive methods for prevention, intervention, and policy development for vulnerable populations of youth and adults. Law (2021) explores and advocates for a universal basic income (UBI) among young adults, specifically highlighting the advantages for young adults experiencing homelessness. Law (2021) argues that a UBI for young adults experiencing homelessness is an economic-strengthening intervention that could help support the housing, educational, and employment needs and goals of this population. Bowie-Viverette (2021) presents findings from a phenomenological study exploring how crisis behavioral health clinicians understand and intervene with patients with malingering behaviors. The author also calls for future qualitative and quantitative research with social workers to better understand and implement best practices to support this population.

Womack (2021) outlines the scarcity of research and supports focused on the intersectional identities of individuals with disabilities who also identify as LGBTQ. An intersectional support group is identified as a potential intervention for use with this population to help understand and meet the unique needs that arise at the intersection of these identities. Janse van Rensburg (2021) reports qualitative findings focused on exploring autism social policy from the perspectives of individuals with autism; these findings are also contextualized within the historical and social context of autism policy in Ontario. Janse van Rensburg (2021) advocates for integrating the lived experiences of persons with autism into policy development to promote meaningful supports and inclusiveness. Lastly, in a book review of de Souza's *Feeding the Other*, an ethnographic work investigating food injustices in food pantries, Mauer (2021) synthesizes and examines de Souza's arguments regarding the influence of neoliberal stigma in the food system. Mauer (2021) highlights the need to emphasize marginalized voices and shift away from privileged perceptions about hunger.

Perspectives on Social Work aims to be an avenue for doctoral students to bolster their skills and scholarship while also working to promote research that embraces social work's mission to empower marginalized populations.

Caitlyn Mytelka, LMSW
University of Houston
Editor

How Can We Improve Long-Term Equity for Today's Young Adults?

Exploring the Potential Advantages of a Universal Basic Income

Lara Law, LMSW

Arizona State University, School of Social Work

Correspondence concerning this article should be addressed to Lara Law, Arizona State University, Southwest Interdisciplinary Research Center, 400 E. Van Buren St., 8 Floor, Phoenix, AZ 85004. Email: lelaw@asu.edu

Abstract

This article explores the potential returns that a Universal Basic Income (UBI) could offer all transition-age young adults, and specifically young adults experiencing homelessness (YAEH). Without sufficient income or resources to maintain housing, YAEH often are unable to experience many of the advantages typically realized by young people in their age-stage of emerging adulthood. These benefits include exploration of their strengths and skill-building through postsecondary education, vocational/technical training, internships, and purposeful employment. A structural intervention, such as a UBI, that supports YAEH and their low-income housed peers in their transition to adulthood is needed for increased equity, long-term poverty reduction and to make the advantages of emerging adulthood available to a wider population of young adults. This article explores the benefits of a UBI by focusing on its individual, unconditional, and unspecified characteristics, and it observes how these features could support the housing stability, employment, education and training goals of YAEH. The article highlights relevant domestic and international UBI pilot programs, including a recent experiment with homeless adults, and also addresses leading counter arguments to a UBI. It concludes by recognizing how a UBI squares with social workers' ethical mandates and it explores the multiple roles social workers could play advocating for and supporting YAEH to access and benefit from economic-strengthening interventions such as UBI.

Keywords: young adults; emerging adulthood; universal basic income; cash transfer; homelessness

How Can We Improve Long-Term Equity for Today's Young Adults?

Exploring the Potential Advantages of a Universal Basic Income

Young adults experiencing homelessness (YAEH), although creative, resilient and highly adaptable in navigating the challenges of homelessness, constitute a low-income population overall (Macdonald, 2013). They strive to meet their basic needs, exit homelessness, and stabilize their housing through both formal means (e.g., employment, public assistance, agency programs) and informal survival strategies. These include selling self-made items, panhandling (i.e., asking for money in public spaces), selling blood or plasma, survival sex (i.e., trading sexual favors for food, clothing, housing, or drugs) or drug

dealing (Ferguson et al., 2012). For many, some combination of these and other activities is often not enough to successfully exit homelessness and achieve housing stability. Without stable housing, or more specifically the income to achieve housing stability, YAEH may miss out on the developmental benefits of their age-stage - emerging adulthood - which include identity exploration, widespread postsecondary education and work opportunities that build toward their goals (Arnett, 2000).

As a subpopulation of homeless adults, YAEH who work in the formal economy often hustle their way through low-skill and low-wage occupations trying to make enough to feed, clothe and house themselves (and families if they have them), yet come up short (Lei, 2013). They experience disproportionately higher rates of mental health challenges than their housed peers (Perlman et al., 2014). While youth connected to higher-income families spend time gaining the skills and qualifications to become economically self-reliant (Furstenberg, 2010), YAEH are typically disconnected from education and vocational settings (Ferguson et al., 2012) that would set them up for longer-term success and stability.

Homelessness, although often influenced by trauma histories, subsequent victimization, and behavioral health challenges, is also the result of structural inequities created by persistent lack of investment in education, housing and healthcare (McKenzie-Mohr et al., 2012; Miller & Bowen, 2020). A structural intervention, such as an unconditional cash transfer program, is needed to support housing stability and advance the employment and postsecondary goals of YAEH and their low-income peers - goals characteristic of emerging adulthood. Specifically, a UBI could allow YAEH the opportunity to build on their strengths and resiliency and develop long-term financial security as well as increase internal stability and wellness. Moreover, a UBI is a superior intervention relative to various housing subsidy approaches because of the dignity of choice it affords recipients. Furthermore, it is provided without limiting conditional rules and the potential for stigmatization that can accompany subsidies. Indeed, a UBI, in combination with increased employment opportunities, has the potential to prevent and address homelessness.

Additionally, a Universal Basic Income (UBI), as opposed to a guaranteed income, is warranted. Although the terms are often used interchangeably (Amadeo, 2020), drawing on recent use (Courtney & Trivedi, 2021) and for the purposes of this paper, a guaranteed income targets a specific population, whereas a *Universal* Basic Income covers the full population of a jurisdiction. A UBI is specifically called for in this article to address the shame and stigma that are associated with population-specific programs. This is necessary because of stigma experienced by YAEH and young adults in general, albeit typically to a lesser degree (i.e., assumptions that they are poor decision-makers).

This article begins by presenting Arnett's (2000) theory of emerging adulthood, including many of its limitations, and briefly provides further background on YAEH. It then focuses on what a UBI program could look like in the United States based on current literature. Next, it explores the possibilities that a UBI could offer to all young adults while specifically addressing how it could support YAEH. It presents evidence from domestic and international UBI pilots and discusses their lessons and application to these populations while addressing the counterarguments to a UBI policy proposal. It concludes by suggesting potential advocacy and support roles for social workers in assisting YAEH to access and take advantage of a UBI.

Emerging Adulthood

At the turn of the century a new age-stage theory was proposed building on the work of Erikson, Levison and Keniston (Arnett, 2000). Arnett's (2000) theory of emerging adulthood contends that over the last several decades, a unique life stage encompassing 18-29 years old has surfaced in developed countries. He asserts that young people in this period now exist subjectively and demographically between adolescence and adulthood, focused on identity development, a growing self-sufficiency, and questions of

“love, work and worldviews” (p. 469). Since it was proposed, the theory of emerging adulthood has garnered considerable traction in the social sciences (Arnett, 2016; Syed, 2015). It has also been subject to considerable criticism, especially in regard to its salience across social class and race (Osgood et al., Settersten, 2012; Silva, 2012; Syed & Mitchell, 2015) as well as housing status (Thompson et al., 2015).

Arnett’s (2000) initial theory was based on what he learned from 300 interviews with an economically diverse cross-section of young people (18-29 years old) and demographic trends which demonstrated longer and wider experiences of higher education and later full-time work, marriage and children. Arnett demonstrated that young adults navigate a high rate of residential instability, many moving in and out of their parents’ homes several times during this period. Emerging adults also experiment with school, training opportunities and employment (Arnett, 2000). Emerging adulthood has become a testing ground, providing many young people the time and space to figure out what they like and dislike, where their strengths lie and where they might fit into the larger society. Although it can be a time of exciting exploration, it can also be experienced as stressful and disorienting. More recently, Arnett (2016) built on this research to add what he called the five features of emerging adulthood: identity explorations, instability, self-focus, feeling in-between and a sense of possibilities or optimism.

Although Arnett’s (2016) scholarship contends the theory of emerging adulthood is essentially consistent across diverse populations of young people, Arnett and others also assert that it is imperative to recognize variations in emerging adulthood within different sociocultural contexts, including among YAEH (Miller & Bowen, 2020). This limitation grounds this article and leads to its call for a structural intervention to play an equalizing role.

Critics of emerging adulthood, such as Côté (2014), point out that limited economic opportunities, and not personal choice, create a prolonged young adulthood for many young people. Others point out that many working-class young people do not have the luxury of emerging adulthood in Arnett’s portrayal of the age-stage (Silva, 2012). Specifically, scholars (Settersten, 2012) point out that African American and Latino young men are disproportionately tracked not into college but into incarceration, and young people who have experienced social service and justice systems (e.g., child welfare, mental health, homeless services) are less likely to complete high school and obtain postsecondary education than their non-system involved peers (Osgood et al., 2010). Young people who are not European American also experience the features of this age-stage differently; they recognize the mismatch between their aspirations (which are often high) and the “structural barriers to achievement and advancement” which lead “some youth to become doubtful that they will be able to realize their dreams” (Syed & Mitchell, 2015, p. 92). Additionally, gender identity also influences how emerging adulthood is experienced; it influences both the choices made by young adults and educational and career options actually available to them (Norona et al., 2016). We can assume from these criticisms that YAEH and many of their marginalized peers do not subjectively experience themselves as emerging adults in Arnett’s use of the term. Considering these limitations, it makes sense to retain the term emerging adulthood as descriptive of the normative age-stage but to refrain from using the term emerging adults with the population of YAEH (see Syed & Mitchell, 2015 for further delineation of the difference in terms).

Other criticism about the theory of emerging adulthood is centered around different conceptualizations of human development. Hendry and Kloep (2007) point out that development is domain specific (e.g., an individual may progress more rapidly in professional pursuits than intimate relationships); it is associated with and contingent on living through experiences rather than chronological age; and it is variable and reversible. In other words, it is not as “smooth” as Arnett describes. These scholars also question whether we are perpetually “becoming” adults throughout the entirety of our adulthood (Hendry & Kloep, 2007). Although thoughtful critiques, these assertions do not negate the common experiences of many young people in this age range and the utility of this life stage terminology to provide a framework for understanding the types of goals and experiences this young adult population commonly pursues.

Young Adults Experiencing Homelessness

YAEH make up a diverse and resilient subpopulation of young adults. On any given night in the United States, more than 38,000 18-24 year old young people (both single and parenting) experience homelessness (U.S. Department of Housing and Urban Development, 2019). Compared to the general population, YAEH experience more childhood trauma, lower education and employment rates, more unplanned pregnancies and higher suicide rates (Narendorf et al., 2020). However, YAEH demonstrate considerable resilience. They often see their homelessness as surmountable; recognize that factors beyond their control contributed to their homelessness; upkeep their cleanliness, health and presentation; rely on networks of social support; and use the arts as outlets for their creativity (Miller & Bowen, 2020). Likewise, many YAEH use geographic mobility, characteristic of this developmental age-stage, to accomplish prosocial goals such as exiting homelessness, pursuing an employment or educational opportunity, or removing themselves from local drug cultures to achieve/maintain sobriety (Ferguson et al., 2013).

YAEH often have intersecting oppressed identities and have endured challenging life experiences (Narendorf et al., 2020). The legacies in the U.S. of slavery, colonization, segregation, discrimination, bias, and inequity have led to a disproportionate number of young people of color being represented in the homeless population; specifically, African American and American Indian young adults are overrepresented (Narendorf & Batiste, 2019). Likewise, among the adult population experiencing homelessness, African Americans are considerably over-represented at 40% of the homeless population and 52% of the homeless families with children (U.S. Department of Housing and Urban Development, 2020). Lesbian, gay, bisexual, transgender, and queer (LGBTQ) young adults, who often contend with rejection, discrimination, stigma and exclusion in their homes and communities, are also disproportionately represented in this population (Morton et al., 2018b).

As mentioned, although the developmental period of emerging adulthood may now be the norm (albeit in Western cultures), its benefits are not available to all young people of this age range. Arnett (2000), and subsequent scholars (De Marco & Berzin, 2008), have noted that low-income young adults are forced to take on adult roles sooner than their peers. YAEH, who were likely to be living in poverty before experiencing homelessness (Morton et al., 2018a), seldom enter an extended period of exploration. Instead, for many YAEH, this life stage is characterized by strain and harsh realities as they take on adult responsibilities and face tension between daily survival and long-term goals (Ferguson et al., 2013). For example, YAEH must pay rent, utilities and living expenses without family support while working to survive rather than working to explore their strengths and hone their skills. Likewise, YAEH often delay or suspend long-term career and educational goals to focus on daily survival, meeting basic needs, and navigating complex homeless systems (Ferguson et al., 2013). On their own, they also often navigate the complicated landscape of postsecondary education and training, without which their occupational and social mobility will be limited (Arnett, 2016). A Universal Basic Income (UBI) could provide considerable support to all young adults, who are navigating an unstable and insecure time in their lives. However, given the economic-strengthening nature of a UBI, this structural intervention has the added potential to change the life trajectories of YAEH.

Universal Basic Income (UBI)

UBI is a policy proposal for a regular, rights-based cash transfer from government to citizen enabling some degree of freedom from financial insecurity (Bidadanure, 2019). Unlike means-tested benefits, UBI is universally provided to everyone within a population, and it is individualized, unconditional and unspecified (i.e., it can be spent on whatever one chooses). Since 2016, there has been a renewed interest in UBI in the U.S. stemming mainly from the fear of worker displacement through automation, as well as

a recognition of income and wealth disparity and the stubbornness of poverty (Bidadanure, 2019). UBI is typically discussed in the U.S. in terms of being distributed on a monthly basis at an estimate of approximately \$1,000/month or above the poverty-level (Bidadanure, 2019; Standing, 2017). An important aspect of any UBI proposal is whether it would lead to the dismantlement of public services or whether it should serve as the base in the new distribution system, alongside other important public services and benefits (Standing, 2017). Some advocates, including presidential candidate Andrew Yang, have proposed that UBI recipients should choose between receiving basic income and other forms of public assistance such as food stamps, while other proponents advocate for “stacking” benefits to help people with the lowest incomes escape deep poverty (Jarvis, 2019). Grounded in the public health and social work codes of ethics, which seek to enhance human well-being, current North American experiments strive to maintain recipients’ access to public assistance (Baker et al., 2020).

UBI has been piloted in several countries under various conditions. UBI trials have been conducted in countries as varied as India, Kenya, Finland and Namibia (Bidadanure, 2019); they also recently have been piloted in the U.S. and Canada with more experiments coming online soon (Hamilton & Martin-West, 2019). Also, though distinct from UBI, President Biden’s \$1.9 trillion American Rescue Plan in response to COVID-19 includes a monthly \$300 payment for each child (the Child Tax Credit), which will establish a basic, guaranteed income for families with children over a 1-year period (DeParle, 2021). Additionally, with respect to populations experiencing homelessness, at least one version of UBI was recently tested with adults experiencing homelessness (Ward, 2020).

Several features of a UBI would benefit all young adults, and YAEH in particular. These features include its individualized, unconditional and unspecified natures. These characteristics provide the basis for supporting the housing stability, employment, and postsecondary education opportunities of young adults and especially YAEH.

Characteristics of a Universal Basic Income

Individualized

UBI is distinct from many other benefit programs in that it would provide support to the individual rather than the family unit or couple. This would make UBI well-suited for the general population of young adults who are in the process of transitioning from reliance on their parents or guardians to relative autonomy. Young adults place a unique financial burden on their families during this age-stage as they often seek support for postsecondary education, housing, health care and other needs. They are the “invisible dependents” who rarely are eligible for other financial supports (Bidadanure, 2012). Low-income families, in particular, do not have the discretionary income to take on these additional expenses and need supplementary support (De Marco & Berzin, 2008). By providing support directly to the emerging adult, UBI has the potential to considerably enhance the financial independence of the young person and, at the same time, free up low-income households to cover their existing expenses.

UBI is also particularly well-suited to support YAEH because, by their very nature, YAEH are distinct and often disconnected from their families of origin. Under these circumstances, a benefit or structural intervention that is directed to the homeless young person as opposed to an estranged family may be most effective. Finally, because UBI is individualized, it would follow the young people in and out of their romantic relationships and would not tie them to unsafe or unhealthy partners from whom they would otherwise leave but for financial dependence. In this way, UBI is recognized as especially empowering for women who may be dependent on the wages of a partner (Bidadanure, 2019). However, recognizing the diversity in gender identity and sexuality in the population of YAEH (Morton et al., 2018b), a UBI is likely to offer freedom and empowerment across both gender and sexuality continua.

Unconditional

The unconditional nature of UBI makes it markedly different than traditional public benefits. In general, it would not need to be applied for and recertified, removing the need to repeatedly interface with often-difficult bureaucracies. Likewise, it would be provided without work requirements or other demands on the recipient, which have been tied to poorer mental health outcomes in the recipient group (Davis, 2019). There is also evidence that traditional public benefits may prolong and worsen poverty through extensive rules and conditionality (Hamilton & Mulvale, 2019). Furthermore, evidence suggests racial and ethnic biases in conditional public benefits (i.e., states with higher populations of African Americans have more excessive rules and offer less assistance to smaller percentages of their population; Hamilton, 2020).

Unconditionality may also be especially relevant considering the stigma associated with public benefit uptake (Stuber & Schlesinger, 2006). By virtue of its unconditionality, UBI as an entitlement program would likely be perceived as dignified. It does not single out a subpopulation as “needy” or somehow “less than” the general population because of a lack of resources. Its universality and unconditionality remove the shame and stigma of traditional public assistance. This feature may be especially important for a population that already experiences stigma associated with homelessness, young adulthood (i.e., assumptions about poor or impulsive decision-making or lack of trustworthiness with financial decisions and resources), and other intersecting identities related to power and oppression.

Many of the unconditional characteristics of UBI (i.e., it would not require recertification or work requirements and not be bound by limiting rules) would help get it in the hands of a population with multiple barriers (e.g., lack of permanent address, missing identification documents, challenges following up with recertification processes because of complicated life circumstances). However, in addition to direct deposit and check delivery, the use of free or no-fee reloadable debit cards, much like are used by Social Security for benefit delivery, will be necessary to ensure a UBI reaches the maximum population. This delivery method will provide the unbanked a means to receive the funds without needing to engage with predatory financial services; additionally, it will provide people experiencing homelessness or housing instability a reliable method, which is not contingent on an address, to receive the funds (Maag et al., 2021). Moreover, as debit cards will be one method used by the IRS to distribute the monthly Child Tax Credit funds (U.S. Department of the Treasury, 2021), we are presented with an immediate opportunity to work through challenges and improve on this delivery method.

Unspecified

The unspecified nature of a UBI means it offers complete choice on how the funds will be spent, which provides another important degree of dignity for recipients. This would affirm the self-determination of YAEH, a population which contends with considerable restrictions in order to meet basic needs, such as stringent shelter rules to have a safe place to sleep that limit personal choice and freedom. The autonomy available through a UBI squares with self-determination theory; it would also provide recipients benefits in terms of functional and psychological wellness (Ryan & Deci, 2019). Under this model, YAEH would be able to choose the housing, food, clothing, and other supplies they need to take care of themselves, thus enhancing their sense of self-esteem and personal agency.

In a recent study with people experiencing homelessness, which could serve as a proxy for a UBI pilot with YAEH in the U.S., Canadian researchers gave 50 adults experiencing homelessness \$7,500 each in a lump-sum payment. The researchers then carefully tracked their spending, as well as that of a control group who received no funds, over the subsequent year. The participants chosen for both groups did not have significant mental health or substance use issues and were recently homeless. The researchers found that the intervention group participants spent the bulk of their funds on food, rent and transportation, and were able to secure housing faster than the control group. By spending fewer days homeless and in

shelters, the recipients actually saved social services more than the cost of the cash transfer, making the case for how such interventions could one day pay for themselves (Foundations for Social Change, 2020). Another interesting finding is that most participants had more than \$1,000 in savings at the end of year (Ward, 2020). In the words of one recipient:

I was living in an emergency shelter, trying to find a way forward. The money gave me the resources I needed to get out of the shelter and push for the social programs and the computer class I needed. It was an important stepping-stone and it gave me a choice. It gave me a chance. (Ward, 2020, p. 1)

In other words, this intervention provided recipients the benefits of choice and self-determination noted above.

Potential Benefits of a Universal Basic Income for Young Adults

Housing Stability

The primary way in which UBI might assist many young adults, and especially YAEH, is by providing them a consistent source of income for housing. As noted, the general population of young adults experience significant residential instability. Many young adults also are subject to unpredictable employment situations, such as temporary, seasonal or gig work. YAEH are especially likely to experience low-wage, inconsistent work and use various survival strategies to meet their needs (Ferguson et al., 2011). A UBI would provide all young adults, and especially YAEH, the consistent means to maintain a lease, pay basic utilities and sustain housing. And importantly, it would allow them the dignity of choice related to safe and stable housing, which is not always available through publicly funded housing programs and even less reliable for sexual minority YAEH (Shelton et al., 2018). Recipients could live with the people they desire or live alone; they could live where they feel the safest; and they would not need to contend with the conditional rules and expectations that still accompany housing benefit receipt. Despite efforts to remove conditionality in Housing First approaches, such as rapid rehousing or housing voucher programs, evidence suggests it remains a characteristic of such programs (Clarke et al., 2020). Although it cannot be assumed that all YAEH would use a UBI on rent, it would likely improve the housing stability for many young people in the population, given that the primary goal among YAEH is typically obtaining safe, affordable, and stable housing (Sample & Ferguson, 2020).

A recent UBI field experiment conducted in Ontario, Canada demonstrates support for the link between a UBI and housing stability. A phenomenological study of UBI recipients who formerly received public assistance found that, compared to the former assistance, the UBI led to greater housing stability, nutrition, connection with family and friends, and ability to manage psychological stress (Hamilton & Mulvale, 2019).

Purposeful Employment

UBI could provide a safety net, especially in terms of housing stability, that affords young adults, and particularly the most indigent young people such as YAEH, the opportunity to explore and take on work that is safe, healthy and meaningful to them. This is important because employment is widely considered to be a social determinant of health (Conyers et al., 2017). Commonly accepted theories contend that work is beneficial materially, as well as psychologically and socially, from the structure, identity, status and connection to a wider world it provides (Jahoda, 1981). More recently, the benefits of work have been posited to include skill mastery, community contribution, connecting with a social network and increasing public recognition (Gheaus & Herzog, 2016).

However, these commonly held views on work fail to account for the breadth of work experiences – especially for the most marginalized members of society. These views do not account for whether employment is temporary or permanent, includes benefits, allows for autonomy, has safe working conditions, or pays a living wage (Conyers et al., 2017). Under many conditions, in particular those that are exploitive, toxic, unsafe, and highly stressful, work can be detrimental to health and well-being. Vulnerable populations often contend with menial and degrading work, and research has found that “any job” is not necessarily better than “no job;” as health can be adversely affected by engaging in poor quality employment (Rueda et al., 2015).

Although YAEH demonstrate high employment engagement rates (Ferguson, 2018), they are an especially vulnerable population in terms of their lack of work experience and seniority, their vulnerability due to unstable housing and related food insecurity, and their desperation for income. Moreover, many YAEH are a part of other demographic groups (e.g., LGBTQ) who experience discrimination in the workplace (Maccio & Ferguson, 2016). A UBI holds the possibility of allowing all young adults the chance to pause, survey their options, and pursue their interests by taking on jobs that will not only just feed and clothe them but set them up for later success. UBI will not tackle or attempt to solve issues of discrimination and other structural inequities faced by young adults, and especially YAEH, but it may provide them the latitude to better move through these instances and seek out other, more affirming, opportunities.

Findings from North American UBI pilot studies support the hypothesis that establishing an income floor will improve connection to, and the quality of work for, recipients. The first year of the recently completed Stockton Economic Empowerment Demonstration (SEED) has been evaluated using a randomized controlled trial (RCT). During the first year of the study, recipients of the basic income increased their full-time employment by 12% (from 28% to 40%), while the control group participants increased full time employment by only 5% (from 32% to 37%; West et al., n.d.). Additionally, results from the Ontario, Canada UBI field experiment demonstrated that beneficiaries moved from low-paying “dead-end” jobs to employment they found to be of higher quality (De Paz-Báñez et al., 2020). These results both suggest that recipients were able to drop part-time shifts or gig work in order to seek better quality employment and experience some freedom from the “capacity limits created by scarcity and precarity” (West et al., n.d., p. 19). YAEH would likely use a UBI, in part, to cover resources needed to obtain or maintain employment given their already active involvement in both formal and informal income-generating activities (Ferguson et al., 2012). For example, a UBI could be used to pay for costs associated with finding work (e.g., phone, internet access, printing resumes for interviews, etc.), starting work (e.g., clothing, or other items required for work such as scrubs or work boots), and maintaining work (e.g., transportation to and from work).

Postsecondary Education

In addition to increasingly seeking employment, pursuing postsecondary education and training are developmentally congruent for their age-stage. Young adults across social classes recognize the value of higher education (Arnett, 2016); similarly, homeless adults report motivation to further their education (Acuña & Erlenbusch, 2009). These findings are important as postsecondary educational attainment may predict employment opportunities which increasingly require higher levels of education (Carnevale et al., 2013).

However, low-income young adults frequently report that they “have not been able to find sufficient financial support to obtain the education they believe they need” (Arnett, 2016, p. 232). Although there are some funding opportunities available to support participation in higher education, such as Pell Grants and scholarships, just 1 in 10 low-income young people complete college by age 25 compared to half of

the population from high-income families (U.S. Department of Education, n.d.). It can be assumed from their instability and survival seeking behaviors that YAEH complete college at an even a lower rate.

Although not without criticism for potential worker exploitation, internships are another means of career exploration as well as skill and resume building frequently pursued by young adults. Recent literature recognizes that internships have proliferated in recent years and that many college students and recent graduates use internships to bolster their career opportunities and to enter fields where internships serve as the only “way in” (Leonard et al., 2016; Panel on Fair Access to the Professions, 2009; Perlin, 2011; Shade & Jacobson, 2015). Internships have also been found to provide valuable “training and experience” for future work, as well as work exposure, development of workplace skills and career self-efficacy for youth who were neither working nor in school (Hull et al., 2018; Silliman et al., 2020). However, evidence suggests that access to internships is affected by social class, ethnicity and educational experience (Perlin, 2011), and unpaid internships “discriminate against those who cannot afford to work unpaid” (Christie, 2008 as cited by Leonard et al., 2016, p. 392).

A UBI could help sustain young adults (i.e., it could be used toward housing, food, books and materials, etc.) while they pursue necessary or desired internships and/or attend postsecondary education and training. YAEH would especially benefit from this financial backing so they can make up for educational opportunities they may have delayed or missed (e.g., completing high school) due to housing instability and subsequently pursue postsecondary education and training.

UBI Counterarguments and Limitations

Any UBI policy proposal for a region or country is likely to stir debate about its feasibility and merits. Although it is beyond the scope of this article to discuss all objections to a UBI, major counterarguments to a UBI, such as the potential for decreased labor supply and its affordability, are addressed below.

Many proponents of UBI celebrate the fact that in effect it will renumerate people for the unpaid labor they already undertake in caring for children or the elderly (Sammeroff, 2018). This is an exciting promise for low-income caretakers, which would include parenting young adults. However, this promise concerns others who fear a UBI would lead a significant portion of the population to drop out of the workforce. The extant research, however, suggests UBI does not have a negative effect on the labor supply. A 2-year UBI Finnish experiment provided a group of participants unemployment benefits without obligation to seek work and without a reduction in benefits if participants began working. Results demonstrated that work was not disincentivized under this initiative; instead, participants’ work motivation increased slightly. Other benefits of this program included improved life satisfaction, mental health and trust in institutions (De Paz-Báñez et al., 2020; Stahl & MacEachen, 2020). Moreover, in their global systematic review, De Paz-Banez et al. (2020) found that the labor supply *increased* among most segments of the population and in the overall population while receiving a basic income. The authors note that young people’s participation was not as high as other subpopulations because they were pursuing schooling. This finding appears to counter the argument that young adults would waste the opportunity of a UBI with poor decision-making regarding spending and how they use their time. Furthering schooling and training are developmentally appropriate activities for this age group.

Another argument against a UBI is affordability, or where the funds will come from to cover the program. In addition to the savings a UBI could create in social services, such as shelter stays noted above, increased taxes or funds reallocated from federal subsidies are typically proposed as funding mechanisms (Standing, 2017). Proponents argue for adjusting tax rates and allowances on the highest income earners and reallocating regressive subsidies for corporations, large landowner farm subsidies and fossil fuel companies to fund a UBI (Standing, 2017). However, according to some scholars (Sammeroff, 2018),

increased taxes are likely to become the burden of workers as opposed to wealthy corporations, who tend to possess more lobbying and political power.

UBI and Roles for Social Workers

Social workers are frequently providers of professional support, resource navigation, and psychotherapy to YAEH. If a UBI were established in the U.S., social workers would likely need to provide increased guidance to this population. First and foremost, many YAEH would need support to ensure they received the benefit by helping them establish and maintain debit cards, bank accounts and/or addresses for checks. Additionally, research demonstrates young adults benefit from money management, economic self-efficacy and problem-solving skill-building (Xiao et al., 2014) as well as goal setting in the form of articulating a “financial vision” (Jorgensen et al., 2019); social workers could help YAEH develop these skills that the general population of young adults are likely gleaned from their parents or guardians and/or the formal educational system. Similarly, they could support YAEH to identify, access and maintain the housing which they may be able to afford with their monthly basic income.

As residential stability has been found to be associated with youths’ ability to access and maintain employment (Slesnick et al., 2018), workforce skill development and connection with internships and employers would be needed as this population became housed. Similarly, social workers could provide support by helping YAEH who were interested to navigate financial aid, scholarships, college and training program applications and admittance. Overall, social workers could seek funding and build programs which provide the range of support services listed here. However, as funding a UBI would likely be a contentious national conversation, leading to some cuts in other supports or programs, some social work positions may be cut in such a reconfiguration of resources. It would be up to social workers to advocate for the retention of still-relevant roles and positions and move into other roles created in this process of change.

Finally, and perhaps most importantly, social workers can be advocates for a UBI paradigm shift. The National Association of Social Workers (NASW)’ *Code of Ethics* (2020) calls on social workers to advocate for improved social conditions and expanded choice and opportunity, especially for vulnerable populations and people living in poverty. Recognizing these imperatives and the degrading and intrusive elements of many public benefits (e.g., attempts to cap child birth rates, drug testing, and the discouragement of saving or wealth accumulation among recipients), social work scholars have recently called on the field to disavow support for such dehumanizing programs and advocate for a UBI as a necessary, dignified metamorphosis (Hamilton & Martin-West, 2019). However, these scholars – and this author – do not advocate for UBI to supplant quality health care, education, retirement and disability supports (Hamilton & Martin-West, 2019). The culling of paternalistic, intrusive programs will be needed, yet a discussion on which benefits should be consolidated into a UBI and which should remain in place is beyond the scope of this article. For now, social workers should heed this call in recognition of the potential benefits for YAEH and other low-income populations and in alignment with our professional values.

Conclusion

A structural intervention, such as UBI, could provide housing and personal stability to a vast number of young adults, and especially meet this need for the almost 10% of young adults (18-25) who experience homelessness each year (Morton et al., 2018a). In turn, this stability could provide a far greater number of young adults the option of benefiting from the opportunities for skill acquisition and personal development normative in their life stage and necessary for economic survival in a post-industrial, knowledge-based economy. Increased postsecondary education and training have the potential to improve long-term earnings and quality of life for YAEH and other low-income young people. Furthermore,

engagement in education and/or employment as a young adult is associated with long-term positive health self-assessment (Lewis & Gluskin, 2018). In addition to serving as a linchpin for YAEH, a UBI could prevent young adult homelessness in other populations at high risk of homelessness (i.e., transitioning from foster care; Courtney & Trivedi, 2021; Dworsky et al., 2013) and for other low-income young people without sufficient funds and/or supports to maintain housing.

The basic premise of a UBI is that it would provide a safety net for each and every member of society. It would help marginalized, low-income populations, such as YAEH, achieve improved financial independence, housing stability, and wellness, and it would recognize the dignity and worth of each person, one of social work's foremost principles (NASW, 2020). If Canada's pilot with adults experiencing homelessness can offer any insight, it is that people experiencing homelessness will be judicious in their spending and use the funds in ways that help them achieve housing and other personal goals. The pandemic-related stimulus checks and shoring up of public assistance and social insurance programs provided in 2020-21 provide a jumping off point to roll out a UBI, which would provide a transformative measure of equity to YAEH and other populations through dignified choice and opportunity to meet their needs and goals.

References

- Acuña, J., & Erlenbusch, B. (2009, August). *Homeless employment report: Findings and recommendations*. National Coalition for the Homeless.
<http://www.nationalhomeless.org/publications/homelessemploymentreport/index.html>
- Amadeo, K. (2020, August 19). Universal basic income: The pros and cons of a guaranteed income. *The Balance*. <https://www.thebalance.com/universal-basic-income-4160668>
- Arnett, J. J. (2000). A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480. <https://doi.org/10.1037//0003-066X.55.5.469>
- Arnett, J. J. (2016). Does emerging adulthood theory apply across social classes? National data on a persistent question. *Emerging Adulthood*, 4(4), 227-235. <https://doi.org/10.1177/2167696815613000>
- Baker, A. C., Martin-West, S., Samra, S., & Cusack, M. (2020). Mitigating loss of health insurance and means tested benefits in an unconditional cash transfer experiment: Implementation lessons from Stockton's guaranteed income pilot. *SSM - Population Health*, 11, 1-6.
<https://doi.org/10.1016/j.ssmph.2020.100578>
- Bidadanure, J. (2012). Short-sightedness in youth welfare provision: The case of RSA in France. *Intergenerational Justice Review*, 1, 22-28. <https://doi.org/10.24357/igjr.6.1.462>
- Bidadanure, J. U. (2019). The political theory of universal basic income. *Annual Review Of Political Science*, 22, 481-501. <https://doi.org/10.1146/annurev-polisci-050317-070954>
- Carnevale, A. P., Smith, N., & Strohl, J. (2013). *Recovery: Job growth and education requirements through 2020*. Georgetown University Center on Education and the Work Force.
- Christie, F. (2008). *Career pathways for graduates into the voluntary/community sector*. University of Manchester.
- Clarke, A., Watts, B., & Parsell, C. (2020). Conditionality in the context of housing-led homelessness policy: Comparing Australia's Housing First agenda to Scotland's "rights-based" approach. *Australian Journal of Social Issues*, 55(1), 88-100. <https://doi.org/10.1002/ajs4.97>
- Conyers, L. M., Richardson, L. A., Datti, P. A., Koch, L. C., & Misrok, M. (2017). A critical review of health, social and prevention outcomes associated with employment for people living with HIV. *AIDS Education and Prevention*, 29(5), 475-490, 2017.
<https://doi.org/10.1521/aeap.2017.29.5.475>
- Côté, J. E. (2014). The dangerous myth of emerging adulthood: An evidence-based critique of a flawed developmental theory. *Applied Developmental Science*, 18(4), 177-188.
<https://doi.org/10.1080/10888691.2014.954451>
- Courtney, M., & Trivedi, S. (2021). The case for providing guaranteed income to kids aging out of foster

- care. *The Appeal*. <https://theappeal.org/the-lab/report/guaranteed-income-for-kids-transitioning-out-of-foster-care/>
- Davis, O. (2019). What is the relationship between benefit conditionality and mental health? Evidence from the United States on TANF policies. *Journal of Social Policy*, 48(2), 249–269. <https://doi.org/10.1017/S0047279418000363>
- De Marco, A. C., & Berzin, S. C. (2008). The influence of family economic status on home-leaving patterns during emerging adulthood. *Families in Society*, 89(2), 208–218. <https://doi.org/10.1606/1044-3894.3736>
- DeParle, J. (2021, March 7). In the stimulus bill, a policy revolution in aid for children. *The New York Times*. <https://www.nytimes.com/2021/03/07/us/politics/child-tax-credit-stimulus.html>
- De Paz-Báñez, M. A., Asensio-Coto, J., Sánchez-López, C., & Aceytuno, T. (2020). Is there empirical evidence on how the implementation of a Universal Basic Income (UBI) affects labour supply? A systematic review. *Sustainability* 2020, 12(22), 1–40. <https://doi.org/10.3390/su12229459>
- Dworsky, A., Napolitano, L., & Courtney, M. (2013). Homelessness during the transition from foster care to adulthood. *American Journal of Public Health*, 103(2), 318–324. <https://doi.org/10.2105/AJPH.2013.301455>
- Ferguson, K. M., Bender, K., Thompson, S., Xie, B., & Pollio, D. (2011). Correlates of street-survival behaviors in homeless young adults in four US cities. *American Journal of Orthopsychiatry*, 81(3), 401–409. <https://doi.org/10.1111/j.1939-0025.2011.01108.x>
- Ferguson, K. M., Bender, K., Thompson, S. J., Maccio, E. M., & Pollio, D. (2012). Employment status and income generation among homeless young adults: Results from a five-city, mixed-methods study. *Youth & Society*, 44(3), 385–407. <https://doi.org/10.1177/0044118X11402851>
- Ferguson, K., Bender, K., & Thompson, S. J. (2013). Predictors of transience among homeless emerging adults. *Journal of Adolescent Research*, 29(2), 213–240. <https://doi.org/10.1177/0743558413487770>
- Ferguson, K. (2018). Employment outcomes from a randomized control trial of two employment interventions with homeless youth. *Journal of the Society for Social Work and Research*, 9(1). <https://doi.org/10.1086/696372>
- Foundations for Social Change. (2020). *Taking bold action on homelessness*. <https://www.in.gr/wp-content/uploads/2021/05/CanadaHomeless.pdf>
- Furstenberg, F. F. (2010). On a new schedule: Transitions to adulthood and family change. *Future of the Children*, 20, 67–87. <https://doi.org/10.1353/foc.0.0038>
- Gheaus, A. & Herzog, L. (2016). The goods of work (other than money!). *Journal of Social Philosophy*, 47(1), 70–89. <https://philarchive.org/archive/GHETGOv1>
- Hamilton, L. (2020). *Welfare doesn't work: The promises of basic income for a failed American safety net*. Palgrave Macmillan. <http://www.palgrave.com/gp/series/14981>
- Hamilton, L., & Martin-West, S. (2019). Universal basic income, poverty, and social justice: A moral and economic imperative for social workers. *Social Work (United States)*, 64(4), 321–328. <https://doi.org/10.1093/sw/swz028>
- Hamilton, L., & Mulvale, J. P. (2019). “Human again”: The (unrealized) promise of basic income in Ontario. *Journal of Poverty*, 23(7), 576–599. <https://doi.org/10.1080/10875549.2019.1616242>
- Hendry, L. B., & Kloep, M. (2007). Conceptualizing emerging adulthood: Inspecting the emperor's new clothes? *Child Development Perspectives*, 1(2), 74–79. <https://doi.org/10.1111/j.1750-8606.2007.00017.x>
- Hull, D. M., Saxon, T. F., Fagan, M. A., Williams, L. O., & Verdisco, A. E. (2018). Positive youth development: An experimental trial with unattached adolescents. *Journal of Adolescence*, 67, 85–97. <https://doi.org/10.1016/j.adolescence.2018.06.006>
- Jahoda, M. (1981). Work, employment, and unemployment: Values, theories, and approaches in social research. *American Psychologist*, 36(2), 184–191. <https://doi.org/10.1007/s10597-012-9490-5>
- Jarvis, J. (2019, October 15). Universal income advocates warn Yang's 'Freedom Dividend' would harm low-income Americans. *The Hill*. <https://thehill.com/policy/finance/465906-universal-basic-income-advocates-warn-yangs-freedom-dividend-would-harm-low-income-americans>

- Jorgensen, B. L., Allsop, D. B., Runyan, S. D., Wheeler, B. E., Evans, D. A., & Marks, L. D. (2019). Forming financial vision: How parents prepare young adults for financial success. *Journal of Family and Economic Issues*, 40, 553–563. <https://doi.org/10.1007/s10834-019-09624-4>
- Lei, L. (2013). Employment, day labor, and shadow work among homeless assistance clients in the United States. *Journal of Poverty*, 17:3, 253–272. <https://doi.org/10.1080/10875549.2013.804479>
- Leonard, P., Halford, S., & Bruce, K. (2016). “The new degree?” Constructing internships in the third sector. *Sociology*, 50(2), 383–399. <https://doi.org/10.1177/0038038515574456>
- Lewis, K., & Gluskin, R. (2018). *Two futures: The economic case for keeping youth on track*. Measure of America, Social Science Research Council. https://ssrc-static.s3.amazonaws.com/moa/PSID2018_FINAL.pdf
- Maag, E., Gwam, P., Torres Rodríguez, S. (2021, April 15). *Delivering tax benefits to people who are experiencing homelessness*. Tax Policy Center. <https://www.taxpolicycenter.org/taxvox/delivering-tax-benefits-people-who-are-experiencing-homelessness>
- Macdonald, S.-A. (2013). The paradox of being young and homeless: Resiliency in the face of constraints. *International Journal of Child, Youth and Family Studies*, 4, 425–446. <https://doi.org/10.18357/ijcyfs44201312695>
- Maccio, E. M., & Ferguson, K. M. (2016). Services to LGBTQ runaway and homeless youth: Gaps and recommendations. *Children and Youth Services Review*, 63, 47–57. <https://doi.org/10.1016/j.childyouth.2016.02.008>
- McKenzie-Mohr, S., Coates, J., & McLeod, H. (2012). Responding to the needs of youth who are homeless: Calling for politicized trauma-informed intervention. *Children and Youth Services Review*, 34(1), 136–143. <https://doi.org/10.1016/j.childyouth.2011.09.008>
- Miller, B., & Bowen, E. (2020). “I know where the rest of my life is going”: Attitudinal and behavioral dimensions of resilience. *Journal of Social Service Research*, 46(4), 553–570. <https://doi.org/10.1080/01488376.2019.1607647>
- Morton, M. H., Dworsky, A., Matjasko, J. L., Curry, S. R., Schlueter, D., Chávez, R., & Farrell, A. F. (2018). Prevalence and correlates of youth homelessness in the United States. *Journal of Adolescent Health*, 62(1), 14–21. <https://doi.org/10.1016/j.jadohealth.2017.10.006>
- Morton, M. H., Samuels, G. M., Dworsky, A., & Patel, S. (2018). *Missed opportunities: LGBTQ youth homelessness in America*. <https://voicesofyouthcount.org/wp-content/uploads/2018/05/VoYC-LGBTQ-Brief-Chapin-Hall-2018.pdf>
- Narendorf, S. C. & Batiste, C. (2019, July 17). To solve youth homelessness we must make race a part of the equation. *Youth Today*. <https://youthtoday.org/2019/07/to-solve-youth-homelessness-we-must-make-race-part-of-the-equation/>
- Narendorf, S. C., Brydon, D. M., Santa Maria, D., Bender, K., Ferguson, K. M., Hsu, H.-T., Barman-Adhikari, A., Shelton, J., & Petering, R. (2020). System involvement among young adults experiencing homelessness: Characteristics of four system-involved subgroups and relationship to risk outcomes. *Children and Youth Services Review*, 108. <https://doi.org/10.1016/j.childyouth.2019.104609>
- National Association of Social Workers. (2020). *Read the code of ethics*. <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
- Norona, J. C., Preddy, T. M., & Welsh, D. P. (2016). How gender shapes emerging adulthood. In *The Oxford handbook of emerging adulthood* (pp. 62–86).
- Osgood, D. W., Foster, E. M., & Courtney, M. E. (2010). Vulnerable populations and the transition to adulthood. *Future of Children*, 20(1), 209–229. <https://doi.org/10.1353/foc.0.0047>
- Panel on Fair Access to the Professions. (2009). *Unleashing aspiration: The final report of the panel on fair access to the professions*. <https://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/227102/fair-access.pdf>
- Perlin, R. (2011). *Intern nation: How to earn nothing and learn little in the brave new economy*. Verso.
- Perlman, S., Willard, J., Herbers, J. E., Cutuli, J. J., & Eyrych Garg, K. M. (2014). Youth homelessness:

- Prevalence and mental health correlates. *Journal of the Society for Social Work and Research*, 5(3), 361–377. <https://www.journals.uchicago.edu/doi/10.1086/677757>
- Rueda, S., Smith, P., Bekele, T., O'Brien, K., Husbands, W., Li, A., Jose-Boerbridge, M., Mittmann, N., Rachlis, A., Conyers, L., Boomer, K. B., Rourke, S. B., and Echo Study Team. (2015). Is any job better than no job? Labor market experiences and depressive symptoms in people living with HIV. *AIDS Care*, 27(7), 907–915. <https://doi.org/10.1080/09540121.2015.1015479>
- Ryan, R. M. & Deci, E. L. (2019). Chapter four - Brick by brick: The origins, development, and future of self-determination theory. *Advances in Motivation Science*, 6, 111-156. <https://doi.org/10.1016/bs.adms.2019.01.001>
- Sammeroff, A. (2018). *Universal basic income: For and against*. Independent Publisher.
- Sample, K., & Ferguson, K. (2019). *It shouldn't be this hard*: Systemic, situational, and intrapersonal barriers to exiting homelessness among homeless young adults. *Qualitative Social Work*, 19(4), 580-598. <https://doi.org/10.1177/1473325019836280>
- Settersten, R. A. (2012). The contemporary context of young adulthood in the USA: From demography to development, from private troubles to public issues. In A. Booth et al. (Eds.), *Early Adulthood in a Family Context* (pp. 3–26). Springer New York. https://doi.org/10.1007/978-1-4614-1436-0_1
- Shade, L. R., & Jacobson, J. (2015). Hungry for the job: Gender, unpaid internships, and the creative industries. *Sociological Review*, 63(S1), 188–205. <https://doi.org/10.1111/1467-954X.12249>
- Shelton, J., DeChants, J., Bender, K., Hsu, H-T., Santa Maria, D., Petering, R., Ferguson, K., Narendorf, S., & Barman-Adhikari, A. (2018). Homelessness and housing experiences among LGBTQ young adults in seven U.S. cities. *CityScape*, 20(3), 9-34.
- Silliman, B., Edwards, H. C., & Johnson, J. C. (2020). Long-term effects of youth work internship: The Project Youth Extension Service approach. *Children and Youth Services Review*, 119(1). <https://doi.org/10.1016/j.chilyouth.2020.105436>
- Silva, J. M. (2012). Constructing adulthood in an age of uncertainty. *American Sociological Review*, 77(4), 505–522. <https://doi.org/10.1177/0003122412449014>
- Slesnick, N., Zhang, J., Yilmazer, T. (2018). Employment and other income sources among homeless youth. *Journal of Primary Prevention*, 39, 247-262. <https://doi.org/10.1007/s10935-018-0511-1>
- Stahl, C. & MacEachen, E. (2020, August 20). Universal basic income as a policy response to COVID-19 and precarious employment: Potential impacts on rehabilitation and return-to-work. *Journal of Occupational Rehabilitation*. [Editorial]. <https://doi.org/10.1007/s10926-020-09923-w>
- Standing, G. (2017). *Basic income: A guide for the open-minded*. Yale University Press.
- Stuber, J. & Schlesinger, M. (2006). Sources of stigma for means-tested government programs. *Social Science & Medicine*, 63, 933-945. <https://doi.org/10.1016/j.socscimed.2006.01.012>
- Syed, M. (2015). Emerging adulthood: Developmental stage, theory, or nonsense? In J. J. Arnett (Ed.), *The Oxford Handbook of Emerging Adulthood* (pp. 11–25). Oxford University Press.
- Syed, M., & Mitchell, L. L. (2015). How race and ethnicity shape emerging adulthood. In *The Oxford handbook of emerging adulthood*. (Issue 1, pp. 87–101).
- Thompson, S., Ferguson, K., Bender, K., Begun, S., & Kim, Y. (2015). Homeless emerging adults: A developmental perspective. In J. Jensen Arnett (Ed.), *Oxford handbook of emerging adulthood*. New York: Oxford University Press.
- U.S. Department of Education (n.d.). *College affordability and completion: Ensuring a pathway to opportunity*. <https://www.ed.gov/college>
- U.S. Department of Housing and Urban Development. (2019). *HUD 2019 Continuum of Care Homeless Assistance Programs Homeless Populations and Subpopulations*.

- <https://www.hudexchange.info/hdx/guides/pit-hic/>
- U.S. Department of Housing and Urban Development. (2020). *Racial Equity*.
<https://www.hudexchange.info/homelessness-assistance/racial-equity/#covid-19>
- U.S. Department of the Treasury (2021, May 17). *Treasury and the IRS announce families of 88% of children in the U.S. to automatically receive monthly payment of refundable Child Tax Credit* [Press Release]. <https://www.irs.gov/newsroom/irs-treasury-announce-families-of-88-percent-of-children-in-the-us-to-automatically-receive-monthly-payment-of-refundable-child-tax-credit>
- Ward, M. (2020, October 9). Canadian researchers gave \$7,500 to people without a home — and the results show the power of universal basic income. *Business Insider*.
<https://www.businessinsider.com/canadian-basic-income-experiment-gives-homeless-people-cash-2020-10>
- West, S., Castro Baker, A., Samra, S., Coltrera, E., Addo, M., Carlson, M., Conway Homes Residents Council, Crowder, P., Cusack, M., Elliott, S., Horn, D., Steckel, J., & Zaghoul, T. (n.d.). *Preliminary analysis: SEED's first year*. Retrieved March 21, 2021, from
https://static1.squarespace.com/static/6039d612b17d055cac14070f/t/6050294a1212aa40fdaf773a/1615866187890/SEED_Preliminary+Analysis-SEEDs+First+Year_Final+Report_Individual+Pages+.pdf
- Xiao, J. J., Chatterjee, S. & Kim, J., (2014). Factors associated with financial independence of young adults. *International Journal of Consumer Studies*, 38, 394–403. <https://doi.org/10.1111/ijcs.12106>

Lara Law, LMSW, is a second-year doctoral student at Arizona State University's School of Social Work and a Graduate Research Assistant at the Southwest Interdisciplinary Research Center. Lara has had the privilege of working around school pushout and juvenile incarceration issues in Mississippi and partnering with homeless young adults in Baltimore City to open and run Maryland's first drop-in center for homeless youth. Lara is interested in engaging in participatory, mixed-methods research related to insecure employment, housing, and economic-strengthening solutions, with and for low-wealth young adults.

Mobile Crisis Clinicians' Experiences with Malingering Patients in Acute Care: A Phenomenological Study

April C. Bowie-Viverette, MSW, MBA

Our Lady of the Lake University, Worden School of Social Service

Correspondence concerning this article should be addressed to April C. Bowie-Viverette, Our Lady of the Lake University, Worden School of Social Service, 411 SW 24th St., San Antonio, TX 78207. Email: acviverette19fl@ollusa.edu

Abstract

Malingering patients have presented continuing challenges to mobile crisis behavioral health emergency clinicians. Through a Theory of Planned Behavior lens, clinicians' experiences with malingering patients were explored, including their attitudes, their anticipated and actual challenges, interventions, and perceived support from leadership and interdisciplinary team members. The author demonstrated clinicians experienced caution in working with patients with malingering behaviors. Five behavioral health clinicians were interviewed virtually, using semi-structured questions, from an urban mobile crisis behavioral assessment team. Moustakas' modified data analysis approach was utilized to identify themes common to these clinicians' experiences. Six themes emerged from verbatim transcript coding and data analysis: 1) malingering recognition; 2) expected scripting; 3) professional helplessness; 4) clinician effectiveness; 5) clinician frustration; and, 6) interdisciplinary team validation. Clinicians experienced similar challenges and frustrations when working with these patients, including a sense of professional helplessness, yet had an overall sense of confidence and effectiveness in identifying malingering patients. This study provided a greater understanding of crisis clinician experiences and provided implications for social work practice.

Keywords: malingering; mobile crisis; social work; behavioral health; acute care

Mobile Crisis Clinicians' Experiences with Malingering Patients in Acute Care: A Phenomenological Study

Malingering patients have presented unresolved challenges to healthcare providers. Malingering patients presenting to acute care settings are difficult to recognize (Zubera et al., 2014). The pace of these settings, combined with a potential lack of patient collateral history, are contributing factors (Zubera et al., 2014). In 2011, 20.2 billion was estimated to have been spent on adult mental disorder malingering disability claimants (Chafetz, 2011; Chafetz & Underhill, 2013). Despite this cost estimate, the frequency of malingering, specific to the clinical setting, is unknown (Bass & Wade, 2018) and was suggested to be as costly as malingering has been found to be in other settings.

There are practice challenges to effectively working with these suspected patients whose primary wants may be underlying unmet psychosocial-spiritual needs, such as insufficient financial and healthcare resources, poor and limited support systems, homelessness, and increased non-emergent psychological distress. The author of this study sought to contribute to knowledge and the literature by exploring the following research question: What are mobile crisis behavioral health practitioners' attitudes, social pressures, and perceptions, including perceived ease or challenge, in working with suspected malingering patients in acute care settings? At the time of this study there were no known empirical studies of mobile crisis acute care behavioral health teams' experiences with malingering patients and no social work inclusive studies despite social workers comprising the largest group of behavioral health providers. As a result, there were no known theoretical frameworks that have previously been utilized to discuss these provider behaviors in working with malingering. The Theory of Planned Behavior (TPB) was the framework used in this study due to research on prediction of health care provider behaviors (Gaston et al., 2008; Klaybor, 1998; Perkins et al., 2007). Costs to the healthcare delivery system, challenges to providers, and the pressing need for standard guidelines on how to manage a malingering patient contributed to the significance of this study (Pasha & Sharma, 2019).

Malingering

Malingering has been defined as “the intentional production of false or grossly exaggerated physical or psychological symptoms motivated by external incentives” (American Psychiatric Association [APA], 2013). The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (*DSM-5*) did not present malingering as a diagnosis but instead as V code V65.2 and Z code Z76.5, which were meant to note issues of clinical significance warranting attention (APA, 2013). At the initial assessment interview, there was often no obvious reason to suspect that a patient was malingering their experiences (McCarthy-Jones & Resnick, 2013). Malingering patients' goals were to have a particular presentation of exaggerated distress guided by patterns and symptoms deviant from patients who suffer with genuine psychiatric disorders (Walczyk et al., 2018). The underlying motivations of these goals have been discussed in adaptational, nurturance, and criminological explanatory models (Velsor & Rogers, 2019).

Malingering has no specific etiology, which presented challenges in estimating prevalence (Alozai & McPherson, 2020). Base rates have important implications for clinicians and were defined as the chances that a malingering patient will present in a clinical setting, such as the acute care environment (Finn, 2009). Malingering was thought to be rare in the clinical setting and more common in the medical-legal settings (Bass & Halligan, 2014). Researchers examining base rates of malingering in different settings surveyed 131 neuropsychologists and showed most malingering cases in a year period ($n = 33,531$) were concerning medical matters ($n = 22,131$) (Mittenburg et al., 2002). Another study (Rumschik & Appel, 2018) found 20% of psychiatric hospital emergency patients were suspected of malingering.

Clinicians tend to assume patient behaviors and complaints are truthful, which presents questions about the detection of malingering and the level of subjectiveness involved (Reznek, 1998). Despite these issues, researchers sought to identify malingering through the use of tests and scales such as the Rey 15 Item Test (Reznek, 2005), which has low sensitivity and high specificity, or the Miller Forensic Assessment of Symptoms Test, which was recommended to not be used in silo to identify malingering (Detullio et al., 2019). Test-retest reliability presented issues as patients' clinical presentations, clinician assessment findings, and scale results can all vary upon repeat interviews resulting in a false positive (Rogers et al., 2010). Also, validity concerns persisted as these tests often rely on patients' truthfulness and rationality in answering scale items (Rogers & Bender, 2003).

Although malingering behavior can initially resemble factitious disorder, a differentiation is that malingering patients were cognizant of their symptom exaggeration, whereas patients diagnosed with factitious disorder had a strong belief their symptoms were genuine despite lack of medical confirmation

(Martin & Schroeder, 2015). Formally labeling a patient as malingering has been a liability concern and viewed as an untruth judgement that could be pursued as libelous, which could be malpractice (Weiss & Van Dell, 2017). The malingering *DSM-5* code has been shielded by the courts, despite the lack of a gold standard for detecting this phenomenon (Weiss & Van Dell, 2017). This lack of absolution was shrouded in clinician assumptions that the patient is a rational historian, unless presenting with apparent psychiatric symptoms to the contrary. Psychiatrists, nurses, social workers, and psychologists appear to have similar viewpoints concerning the concept of malingering patients (Murdach, 2006). As a result, there have been immeasurable impacts in crisis clinicians' provision of accurate care and timely interventions. This is significant for behavioral health clinicians because of a common concern with revolving door patients and the concern of patients discharged with unmet and unaddressed needs.

At the time of this study, to the author's knowledge, there was limited qualitative research focused on the clinical experiences of externally consulted mobile crisis behavioral health clinicians who work with these suspected patients in acute care emergency settings, including emergency rooms (ER) and urgent care facilities. Previous research studies have focused on detection of malingering behaviors, methods of intervention, and most often, studies were focused on psychiatrists' experiences (Rumschik & Appel, 2018; Zuber et al., 2014).

Clinical Experiences with Malingering

At the time of this study, there was limited peer reviewed literature attentive to non-physician crisis providers' experiences with malingering patients. Most empirical studies focused on psychiatrists (Rumschik & Appel, 2018). Rumschik and Appel (2018) conducted a study of 14 attending psychiatrists and 405 patients of an inpatient psychiatric unit at a medical hospital and found a 33% (n = 134) suspicion of malingering with 20% (n = 81) of them strongly suspected of malingering. Murdach (2006), a clinical social worker, wrote a review of malingering. In nursing, there were reviews of malingering patients mostly aimed to inform nurses' experiences and offer implications for practice with these patients (Mason et al., 2014). Psychologists published articles similar to the aforementioned social work and nursing articles; however, a difference is an increased focus on using scales and testing in practice implications (McDermott & Sokolov, 2009).

Trained and seasoned mental health clinicians can be deceived by patients (McCarthy-Jones & Resnick, 2013). Nursing implications explained the importance of accuracy in recognition of malingering so as to avoid providing inappropriate prescriptions (Mason et al., 2014). Implications of a successful malingering patient, at a clinician level, included an inability to properly understand a patient's actual needs, appropriately intervene, and reduce liability risks. At a facility level, consequences of patient malingering included misdirection of facility staffing and bed resources. An accurate knowledge of the phenomenon associated with malingering and a clear understanding of prevalence and base rates has important implications for clinicians' proper assessment of this problem (McCarthy-Jones & Resnick, 2013). Seasoned behavioral health clinicians have often been unwilling to confront the patients due to concern about risk management (Weiss & Van Dell, 2017) and concern over the impact confrontation could have on the helping relationship (Waite & Geddes, 2006).

Theoretical Underpinning

The Theory of Planned Behavior (TPB) has been used to inform previous studies of healthcare professionals' behaviors (Kelly et al., 2012; Kortteisto et al., 2010;) and found to have better predictive power and relevance to healthcare providers (Millstein, 1996; Godin et al., 2008). Behavior intentions were based on three factors related to behaviors: attitude, subjective norm, and perceived control (Ajzen, 2020).

Previous studies noted the applicability in exploring and explaining healthcare professionals' experiences and in designing theory-based interventions to change professionals' behaviors (Perkins et al., 2007; Thompson-Leduc et al., 2015). The central themes of this theory applied to anticipated clinician experiences included: 1) attitudes, which were the emotional and rational reasoning used to decide whether to label a patient as malingering; 2) social pressures or the subjective norm, which is the validation sought from agency supervisors and patient acute care attending physicians about their recommendation to discharge a suspected malingering patient; and, 3) perceived ease or challenge performing a behavior, including anticipation of obstacles (Thompson-Leduc et al., 2015).

Methods

This study was approved by the University Institutional Review Board. A purposive sample of five participants was recruited during a monthly team meeting of a well-established behavioral health mobile crisis team of over 50 clinicians located in a major city within the South-Central United States. Participants were recruited during an optional monthly team meeting. Meeting attendance was optional due to the nature of the 24/7 on-call work in the field.

Data Collection

Dukes (1984) recommended three to ten as a sample size for a phenomenological study. Five participants was within the range of number of interviews recommended. Saturation was apparent after coding verbatim transcripts of these participants; because no new themes emerged from these five individual interviews, recruiting ceased and additional interviews were not pursued (Creswell & Poth, 2018). It is important to note that this team consisted mostly of PRN clinicians who rarely visit the office. This may have affected data collection efforts.

Participants voluntarily signed up via circulated sign-up sheet, which included a request for their contact information, such as email addresses and phone numbers; professional credentials, such as whether they are a social worker, a professional counselor, or a registered nurse behavioral health clinician; and, best day and time to reach them. This sign-up sheet was circulated to all meeting attendees after a brief study introduction and collected at the end of the team meeting. Informed consent forms were emailed to interested participants, completed, and returned via email to the researcher prior to start of the virtual interview.

The study investigator contacted participants via phone, a maximum of three attempts, to schedule interviews. There were two attempts via phone; if the first attempt via phone resulted in no answer, a voicemail was left; an email was sent as a reminder about the interview. Next, if no return call was received within three days, a third phone call was attempted and a voice message was left. Data were collected November 2019 and analyzed Spring and Summer of 2020. Field notes were taken immediately following sessions.

Rigor and Trustworthiness

Methodological rigor was achieved by use of Burns (1989) method and through verification, validation, and validity of data collected (Meadows & Morse, 2001). The phenomenon was defined according to a literature review, the author's past clinical experiences were bracketed, an adequate sample was analyzed, including interviewing until saturation, and field notes were kept to increase rigor (Creswell & Poth, 2018; Meadows & Morse, 2001). Study design, method, and data analysis was examined by an experienced qualitative, phenomenological researcher, avoiding methodological incongruence (Burns, 1989). Two participants were provided the findings to review, and they provided feedback confirming accuracy for validation (Meadows & Morse, 2001).

Data Analysis

This phenomenological study data was analyzed using Moustakas's (1994) modified approach to answer the research question. This method involved analysis using systematic steps and guidelines for developing textual descriptions (Creswell & Poth, 2018). Moustakas's modified approach to analysis required a determination that the research question was best examined by a phenomenological approach as well as identification and description of a phenomenon. Findings were useful to help with understanding clinicians' experiences for the development of implications for social work practice due to the costly problem that malingering presents to agencies, facilities, insurances, and society. This was important because it was crucial in the provision of effective interventions and services. Also, working with malingering patient behaviors can contribute to burnout due to feelings of ineffectiveness and compassion fatigue (Eliacin et al., 2018; Garcia et al., 2016).

Next, this approach required specification of the assumptions of phenomenology. Clinician views of malingering patients were described. Also, bracketing the researcher's own clinical practice experiences with malingering patients and reflexivity (Jootun et al., 2009) was practiced by the study researcher.

Moustakas (1994) required data collection from clinicians who had experienced this phenomenon. Theming of data based on significant statements was completed. Saldana (2016) explained that the goals of the study determines the coding method selected. Recorded interviews were transcribed verbatim followed by sentence-by-sentence deductive coding of all transcripts. This resulted in 157 codes that were clustered into six themes. Codes with similar meanings were re-coded. Clusters of meaning were developed and themed based on clinicians' significant statement analysis using horizontalization. Finally, these significant statements were examined and analyzed to develop textural and structural descriptions of what the clinicians experienced with the phenomenon (Creswell & Poth, 2018). The process of reading, re-reading, and coding the data was iterative.

Findings

Table 1 presents the demographics of the sample. As noted, 80% (n = 4) of the clinicians were female. The majority were African-American (n=3, 60%), clinical social workers (n= 4, 80%), a professional counselor (n=1, 10%), and a registered nurse (n=1, 10%), all with over 2 years of experience working on a mobile crisis response team. One clinical social worker had a role of program manager, and another had the role of clinical manager; these managers assessed patients in addition to their daily management duties.

Table 1. Sample Characteristics

Characteristics	n	%
Male	1	20
Female	4	80
Race/Ethnicity		
Black/African American	3	60
Caucasian	2	40
Licensed Profession		
Clinical social worker	3	31
Professional counselor	1	20
Registered Nurse	1	20

Table 2 includes selected examples of significant statements with their formulated meaning. Six themes emerged from data analysis: 1) malingering recognition; 2) expected scripting; 3) professional helplessness; 4) clinician effectiveness; 5) clinician frustration; and, 6) interdisciplinary team validation. Table 3 provides an example of two theme clusters with their associated meaning. These themes are discussed below.

Table 2. Selected Examples of Significant Statements of Clinicians and Related Formulated Meaning

Significant Statement	Formulated Meaning
(1) I try to find out if the symptoms are real and why they are doing this.	(1) Clinicians assessed patients and their symptoms prior to considering a patient as malingering.
(2) ...a malingering patient, well a lot of times sometimes they can present as a homeless patient, you know you can tell that they're homeless, you can look at their feet, sometimes you can tell they've been walking a lot, they're dirty, ah but not just because they're homeless does not automatically mean that they're malingering.	(2) Malingering patients often had unmet bio-psychosocial needs; this was a red flag that clinicians considered as they continued their assessments.
(3) They want to be removed from their existing lifestyle and they want others to do for them but unfortunately they're not willing to do for themselves.	(3) A malingering patient, who was assessed to have the capacity to follow through, lacked motivation to follow through on clinician recommendations and resources that can assist in resolving their unmet needs.
(4) I don't get really angry with them, but I do call him out on it.	(4) Anger was felt but was not displaced onto the malingering patient.
(5) When I first go in or whatever you know I tried to maintain a, you know, professional but friendly demeanor with the patient. I try to ask a few questions to kind of get to know them, tell them a little bit about me and you know kind of get into a comfortable conversation with them at first.	(5) A professional composure was required to effectively establish rapport.

Table 3. Example of Two Theme Clusters with Examples of Their Associated Formulated Meanings.

Professional Helplessness	Clinician Attitudes
(1) A feeling and sense of impossibility with getting positive outcomes.	(1) Hoping not to become jaded towards working with these patients.
(2) Worry about the patients' unmet needs that persist outside of the scope of the intervention and inability to ameliorate their stressors.	(2) Feeling emotionally drained when working with these patients.
(3) The uncertainty of what was truly motivating the malingering behavior.	(3) Important work that is treated as significant.
(4) Uncertainty and consequence doing this work.	(4) Sincere interaction.

(5) Patients often had no shelter and would show disinterest in, decline, or refuse resource options. (5) Staying hopeful with work.

Theme 1: Malingering recognition. Clinicians were collectively confident in their identification of malingering patients. They all denoted that malingering patients were interested in a secondary gain. All reported experiences with recognizing malingering behaviors in patients who reported inconsistent complaints, histories, and stories. Clinicians often experienced the same patients presenting malingering; therefore, their experiences provided them opportunity to recognize this. Their identification and recognition of malingering was illustrated by these quotes:

The malingers at times be [sic] very persistent about remaining where they are and continuing to insist upon symptoms. However, there is no sign of distress, there's no symptomology to substantiate what they are verbally saying so you don't see that.

"It is their verbal communication that is in conflict with what is presenting and those are things that we mostly look at to identify a malingering patient."

Theme 2: Expected scripting. Once clinicians identified a patient as malingering, whether through report from interdisciplinary team staff, known patient history, or at an initial face to face meeting, they expected the patient's scripted presentation of their stories. These patients presented with rehearsed, prepared stories, which were a collection of inconsistent symptoms, experiences, and histories. This included stalling to prolong their time in the hospital. Clinicians' reports of these experiences are noted below.

So, I mean...a couple of thoughts you know obviously I was concerned about, you know, where they are going to live; you know, kind of worried about that, kind of knowing they're not going to be very happy when I'm telling them that we're going to discharge them.

"I mean, for instance, I may come across a patient who, they'll have certain like key phrases that they'll use in the ER where they're pretty much scripted."

Theme 3: Professional helplessness. These patients had persisting unmet psychosocial needs. Because many malingering patients consistently presented lacking basic needs, clinicians felt a sense of inability to effectively intervene by immediately resolving a patient's problems and expressed a sense of helplessness; this was a less prevalent theme. Clinicians expressed difficulty adequately addressing secondary gain motivators that were within the scope of their human service practice due to the nature of the crisis environment. Some local community resources were not available to immediately resolve many of these basic need issues. Clinicians' sense of helplessness was noted by this quote:

I work really hard to get the resources for them that actually would be beneficial with them, get them connected with, sometimes, the county mobile crisis outreach team or some type of case management services in the home or in the community and give them a good set of resources that would be beneficial to them.

Theme 4: Clinician effectiveness. Clinicians sought to identify patients' core issue. This often resulted in gentle confrontation and assertiveness about their suspected malingering behavior. Rapport building was reported as key to developing dialogue and building trust in hopes that patients can reciprocate truthfulness and disclose their true needs. A clinician stated, "Just try to take an approach to let them know that, you know, that I'm willing to help them out if they're able to just kind of, you know, be forthcoming with me..."

“When they see that you're genuinely concerned, you know, then you can sometimes be more effective with them.”

I'll talk him up a little bit to kind of get them comfortable with me, and if I feel they're malingering, I'll just kind of stop for a minute, look him in the eye maybe give him the [facial expression] and say, ‘OK, now tell me why you're really here.’

Theme 5: Clinician attitudes. Clinicians thought it was important to have reported that they maintained an unbiased, objective approach to working with these patients. Two clinicians said that they wanted to avoid becoming jaded due to their encounters with this work. Frustration was collectively expressed; however, one clinician indicated that she does not let this affect her as other colleagues have. Clinicians' attitudes are illustrated by these quotes:

Well, um, it's frustrating because obviously our job is to, you know, help people that have mental illness and addiction and get them to the right... ah right facility, the right level of care, and when somebody is, you know, feigning symptoms they did [sic] that they don't really have, I think, you know it can tend to make quick clinicians kind of angry.

“Malingersers can be very disappointing to serve. It's, uh, it's not a population I enjoy engaging.”

Theme 6: Interdisciplinary team validation. Clinicians' colleagues were primarily described as validating and supportive of their approaches to working with these patients and their recommendations. This included managers and direct care hospital ER interdisciplinary team members. The following illustrated clinicians' perceptions of support for how they intervene with malingering patients:

“... if you have supportive ER staff doctors who are used to dealing with malingersers, they are usually pretty good about backing you up and ah discharging the patient.”

“So they've actually been very supportive again. If I... I have to call my supervisor after I've done the assessment and go over what, you know, I think should happen with the patient, and they pretty much back me up.”

Most of the time they're the ones that initially think the patient is malingering as well so if I validate that I think...that, they are generally supportive of that for the most part. I've had a few situations where, you know, they really believed...the patient story versus me [sic] but very seldom. I think that most of the experienced ER nurses and doctors pretty adapted it [sic], seeing through it a lot of times as well. And of course, they're trying to move people through the ER and you know and discharge people that don't belong there so, so I think you know we generally tend to agree.

Discussion

In this study, the TPB framed clinicians' experiences working with malingering patients. Overall, findings were similar across disciplines and demonstrated clinicians' descriptions of this phenomenon were in line with the *DSM-5* definition, which included the terms “secondary gain” (APA, 2013). Clinicians' attitudes and social pressure experiences were often aligned with the literature and predictable (Godin et al., 2008); however, at times these were misaligned, which coincided with the known concerns associated with detection of malingering (McCarthy-Jones & Resnick, 2013; Bass & Halligan, 2014). Clinicians believed that they were capable of identifying malingering, which was explained by perceived behavioral control as part of the TPB, which clinicians based on past experiences, anticipated obstacles, and involved perceived ease or challenge with performing a behavior (Thompson-Leduc et al., 2015;

LaMorte, 2019). Clinicians were well experienced as part of a mobile assessment team that serviced many acute care settings in their area, which is one of the top five populous cities in the United States. As a result of their past clinical experiences, their confidence translated to clinical skill with identifying malingering patients. Clinicians collectively experienced recognizing malingering patients during initial interviews, which was counter to the literature that stated that there was often no obvious reason to suspect a patient as malingering upon initial assessment (McCarthy-Jones & Resnick, 2013). One clinician stated, “a twist and turn in their story makes you think, what’s going on with this assessment?” Hesitation with labeling was suggested in the literature; however, these clinicians expressed comfort and a sense of accuracy with labeling patients as malingering. This could be due to their reports of some suspected malingering patients presenting to the same facilities at certain seasons of the year or at certain predictable times, which became apparent as a result of clinicians’ years of experiences at these particular facilities. They recognized these patients had exaggerated and inconsistent presentation of symptoms, which coincided with the literature (Walczyk et al., 2018). This comfort was contrary to what literature found, which noted that clinicians could have been deceived by these patients (McCarthy-Jones & Resnick, 2013) and that this problem could be difficult to recognize (Zubera et al., 2014) and difficult to diagnose (Rumschik & Appel, 2018). There could be risks associated with labeling a patient as malingering (Weiss & Van Dell, 2017).

Clinicians noted malingering patients were scripted in their malingering behaviors, suggesting that prepared patients could conflict with the clinicians’ reported goal to empower these patients. A clinician described this as, “...they kind of know all the answers to all the questions that you're going to ask them. They know the right things to say.” This finding was aligned with the theoretical explanations for malingering behaviors (Velsor & Rogers, 2019) and confirmed why a person-centered approach, which theorized that patients are resourceful and capable of finding the solutions to their problems (Cain, 2010) may not be ideal in working with these patients. Also, other unhelpful approaches include making commitments, excessive pressuring, and having an adversarial stance of judging and blaming. Mild confrontation while maintaining professional clinical distance was recommended in working with these patients (Murdach, 2006), which coincides with clinician reports that they have confronted patients about their malingering behavior.

Despite a sense of professional helplessness, and the concern over effectiveness, clinicians’ attitudes exemplified overall confidence in their effectiveness when it came to recognizing these patients and appropriately recommending them for discharge with resources. Accurate knowledge and assessment were paramount to understanding this phenomenon (McCarthy-Jones & Resnick, 2013). Clinicians’ professional helplessness stemmed from the patient’s unmet needs, which were often needs that required follow up beyond their crisis setting scope of practice. They were intervening by taking steps to establish rapport, remaining non-judgmental, and positioning themselves to attain trust from these patients. TPB suggested their effectiveness was based upon their perceived behavioral control (Godin et al., 2008).

Use of therapeutic skills and empathetic listening can help usher patients toward revealing and unmasking their actual problems and concerns (Murdach, 2006). The theme of clinical effectiveness aligned with this recommendation as clinicians explained it was a requirement of rapport building to learn the core motivation of these patients. Drawing out paradoxes in complaints and symptoms and a gentle revealing of these inconsistencies was appropriate (Murdach, 2006). Clinicians recognized the importance of attentiveness to these contradictions in patients’ narratives when they were completing their assessments.

The social pressure and norms of human service work’s strengths-based practice perspective indicated clinician sense of helplessness was accurate. Clinicians sought to ameliorate client challenges and suffering and address unmet needs by providing education and resources. This was in line with a strengths-based approach (McKnight, 2016). Clinicians sought to identify patient core motivations for presenting at the acute care facilities. They were forward in gently confronting patients, inquiring about

their patient's honesty and truthful reporting of their actual unmet needs: "sometimes it does take being much more assertive than you would in [sic] normal patients, and in the process sometimes assertiveness is required."

Clinicians' decisions about working with malingering patients were unique and individual to them (Godin et al., 2008). Their participation within an interdisciplinary team and reliance on physicians to make the final decision as to patient disposition was native to these mobile assessment acute care clinicians' roles and part of the social norm. Clinicians experienced validation by their peers, which meant their peers supported their treatment or discharge recommendations for these malingering patients. This finding was consistent with the literature indicating clinician behaviors were influenced by the expected outcome to discharge these patients (LaMorte, 2019).

Clinicians anticipated obstacles when working with these patients (Thompson-Leduc et al., 2015). One clinician stated, "...sometimes working with the malinger can be frustrating especially if you are pressed for time and/or if the person is highly experienced." A self-inventory of attitudes and emotions in working with malingering patients was vital to ensure the National Association of Social Worker's ethical principle of respecting the dignity and worth of the person and commitment to clients is upheld (NASW, n.d.); cautious use of language used when working with interdisciplinary teams is important. A strengths-based approach and reframing promotes effectiveness.

This study provided evidence that experience improves clinicians' recognition and identification of malingering behaviors, including specific malingering behaviors encountered, intervention methods, and agency and hospital team support. A focus on the core motivation of the drivers of malingering behavior was explored, and studies found malingering patients expected secondary gains as a result of exaggerating or deceiving their health care providers about their psychiatric symptoms (Zubera et al., 2014). These patients can be managed by a focus on verifiable and well-defined immediate problems (Murdach, 2006). Use of collateral history to ensure a comprehensive biopsychosocial history is vital and yet can present ethical issues. This could contribute to difficulty in confirming suspicion of malingering. Clinicians used collateral history to validate or invalidate malingering patients' presenting problems.

Implications for Social Work

Social worker implications are associated with the National Association of Social Worker's (NASW) healthcare practice standard (i.e., NASW, 2016). Social workers are mandated to adhere to the healthcare practice standards and be aware of the healthcare setting issues that they work in (NASW, 2016). Although clinicians are unable to follow up with clients beyond the acute care setting, these clients can be referred to other resources. For example, if the patient was insured, they may have access to managed care case management resources (NASW, 2016).

Additionally, inexperienced and experienced social workers are cautioned to consider the impact of malingering patients' behaviors beyond the hospital environments, such as abuse of health insurances, including Medicare and Medicaid (Murdach, 2006), and how this can be considered fraud and abuse. Health care providers are covered entities of the Health Insurance Portability and Accountability Act that states, "a covered entity may disclose to a law enforcement official protected health information that the covered entity believes in good faith constitutes evidence of criminal conduct that occurred on the premises of the covered entity" (Health Insurance Portability and Accountability Act, 1996). Reporting malingering could be a deterrent (Rumschik & Appel, 2018), yet could present an ethical dilemma as confidentiality is an ethical mandate, particularly of social workers. Clinicians are also recommended to consider the False Claims Act which forbids billing for unnecessary services (The United States Department of Justice, n.d.) when considering appropriate service referrals.

Murdach (2006) recommended social workers consider the power dynamic in the clinician-client relationship since power-sharing can maintain a malingering patient's use of deception. This is contradictory to empowerment theory which seeks to strengthen malingering patients so they can take action to improve their situations (Turner & Maschi, 2015).

Thorough assessments, detailed documentation, and use of supervision and consultation is key. Malingering patients can be litigious (Murdach, 2006). Due diligence, attention to these patients' needs and complaints, and thorough consultation and documentation is imperative (Murdach, 2006). Clinicians in this study did not mention a concern for risk in discharging these patients; instead, they indicated an experience of validation by the interdisciplinary team at the hospital and also from their agency management, who they review their cases with, which may have enhanced their comfort with recommending discharge.

Empathetic listening can enhance rapport and contribute to de-escalation of untruthfulness. A thorough review of physician, nurse, and sitter notes, as well as rapport with the team, can promote clarity in arriving at a malingering diagnosis, and also promotes an effective discharge plan that is reinforced by each care provider during their dialogue with the patient at discharge. This can influence patient motivation to follow up on social work recommended resources.

Mild confrontation of known repeat malingering patients, while maintaining appropriate clinical distance, is recommended (Murdach, 2006) and use of collateral history is imperative. Consultation and supervision are suggested to recognize and process challenges in practice with suspected malingering patients to remain sensitive, empathetic and compassionate when working with these patients.

Limitations

The limitations of this study included: 1) sample size; 2) sample composition (the sample was comprised of only experienced clinicians with no novice clinicians recruited, and the sample included varied provider types); 3) at the time of this study the author found limited literature and empirical research specific to mobile crisis clinicians, therefore, there were no previous studies as an exemplar; 4) limitations of the TPB were not discussed, such as the assumption that decision making is linear; 5) epistemological constraints associated with a concept that has been deemed difficult to detect; and, 6) findings are not generalizable. TPB does not account for additional clinicians and assumes clinicians have the experience and practice knowledge despite widespread detection difficulty. Notwithstanding these limitations, this study provided important contributions to behavioral health clinicians and their interdisciplinary teams who work in acute care crisis stabilization settings.

Future Research

Future research that focuses on master's level social workers, who are the largest group of behavioral health providers, and utilizes a grounded theory research approach is suggested. This will provide an exemplar and greater understanding of best practices. Additionally, replicating empirical studies conducted with neuropsychologists and psychiatrists with samples of social workers, as well as research on base rates, are suggested.

Conclusion

Caution is recommended in labeling a suspected malingering patient. Thorough assessment, including collateral information from various sources, is vital. Despite this recommended caution, experienced

clinicians rely on their years of experience and judgment to recognize a malingering patient and do not use the language of “suspected.” Despite a varied sample of a registered nurse, 3 social workers, and one licensed professional counselor, interview findings were very similar. This study sought to explore clinicians’ experiences with suspected malingering patients and showed these ongoing uncertainties in detection demonstrated a collective sense of stifling in practice. Given the risks, clinicians were rightly cautious in labeling a patient. An awareness of ethical issues and risks of working with malingering patients, while assertively intervening and utilizing an interdisciplinary team approach, are best practices.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Publishing.
- Ajzen, I. (2020). Theory of planned behavior: Frequently asked questions. *Human Behavior and Emerging Technologies*, 2, 314-324. <https://doi.org/10.1002/hbe2.195>
- Alozai, U., & McPherson P.K. (2020). Malingering. *StatPearls*. <https://www.ncbi.nlm.nih.gov/books/NBK507837/>
- Bass, C., & Halligan, P. (2014). Factitious disorders and malingering: Challenges for clinical assessment and management. *Lancet*, 383(9926), 1422–32. [https://doi.org/10.1016/S0140-6736\(13\)62186-8](https://doi.org/10.1016/S0140-6736(13)62186-8)
- Bass, C., & Wade, D. T. (2019). Malingering and factitious disorder. *Practical Neurology*, 19(2), 96–105. <https://doi.org/10.1136/practneurol-2018-001950>
- Burns, N. (1989). Standards for qualitative research. *Nursing Science Quarterly*, 2(1), 44–52. <https://doi.org/10.1177/089431848900200112>
- Cain, D. (2010). *Person-centered psychotherapies*. APA Books.
- Chafetz, M. (2011). The psychological consultative examination for Social Security Disability. *Psychological Injury and Law*, 4, 235-244. <https://doi.org/10.1007/s12207-011-9112-5>
- Chafetz, M., & Underhill, J. (2013). Estimated costs of malingered disability. *Archives of Clinical Neuropsychology*, 28, 633-639. <https://doi.org/10.1093/arclin/act038>
- Creswell, J.W. & Poth, C.N. (2018). *Qualitative inquiry and research design* (4th ed.). Los Angeles: SAGE.
- Detullio, D., Messer, S. C., Kennedy, T. D., & Millen, D. H. (2019). A meta-analysis of the Miller Forensic Assessment of Symptoms Test (M-FAST). *Psychological Assessment*, 31(11), 1319–1328. <https://doi.org/10.1037/pas0000753>
- Dukes (1984). Phenomenological methodology in the human sciences. *Journal of Religion and Health*, 23(3), 197-203. <https://doi.org/10.1007/BF00990785>
- Eliacin, J., Flanagan, M., Monroe-DeVita, M., Wasmuth, S., Salyers, M. P., & Rollins, A. L. (2018). Social capital and burnout among mental healthcare providers. *Journal of Mental Health*, 27(5), 388–394. <https://doi.org/10.1080/09638237.2017.1417570>
- Finn, S. E. (2009). *Incorporating base rate information in daily clinical decision making*. J. N. Butcher (Ed.). *Oxford Handbook of Personality Assessment*, 140–149. <https://doi.org/10.1093/oxfordhb/9780195366877.013.0008>
- Garcia, H. A., McGeary, C. A., Finley, E. P., McGeary, D. D., Ketchum, N. S., & Peterson, A. L. (2016). The influence of trauma and patient characteristics on provider burnout in VA post-traumatic stress disorder specialty programs. *Psychology and Psychotherapy*, 89(1), 66–81. <https://doi.org/10.1111/papt.12057>
- Gaston, G., Bélanger-Gravel, Martin, & Jeremy, (2008). Healthcare professionals' intentions and behaviours: A systematic review of studies based on social cognitive theories. *Implementation Science*, 3, 36–36. <https://doi.org/10.1186/1748-5908-3-36>
- Godin, G., Bélanger-Gravel, A., Eccles, M., & Grimshaw, J. (2008). Healthcare professionals' intentions and behaviours: A systematic review of studies based on social cognitive theories. *Implementation Science*, 3, 36. <https://doi.org/10.1186/1748-5908-3-36>

- Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191 (1996).
<https://aspe.hhs.gov/report/health-insurance-portability-and-accountability-act-1996>
- Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: Promoting rigour in qualitative research. *Nursing Standard*, 23(23), 42–46. <https://doi.org/10.7748/ns2009.02.23.23.42.c6800>
- Kelly, P. J., Deane, F. P., & Lovett, M. J. (2012). Using the theory of planned behavior to examine residential substance abuse workers intention to use evidence-based practices. *Psychology of addictive behaviors: Journal of the Society of Psychologists in Addictive Behaviors*, 26(3), 661–664. <https://doi.org/10.1037/a0027887>
- Klaybor, G. R. (1998). *An application of the theory of planned behavior on clinical social workers' utilization of the DSM-IV: An exploratory study*. (Unpublished doctoral dissertation). University of Houston, Houston, Texas.
- Kortteisto, T., Kaila, M., Komulainen, J., Mäntyranta, T., & Rissanen, P. (2010). Healthcare professionals' intentions to use clinical guidelines: A survey using the theory of planned behavior. *Implementation Science*, 5, 51. <https://doi.org/10.1186/1748-5908-5-51>
- LaMorte, W. (2019, September 9). *Theory of Planned Behavior*. Boston University School of Public Health. <http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories3.html>
- Martin, P., & Schroeder, R. (2015). Challenges in assessing and managing malingering, factitious disorder, and related somatic disorders. *Psychiatric Times*, 32(10).
<https://www.psychiatrictimes.com/special-reports/challenges-assessing-and-managing-malingering-factitious-disorder-and-related-somatic-disorders>
- Mason, A. M., Cardell, R., & Armstrong, M. (2014). Malingering psychosis: Guidelines for assessment and management. *Perspectives in Psychiatric Care*, 50(1), 51–57. <https://doi.org/10.1111/ppc.12025>
- McDermott, B. E., & Sokolov, G. (2009). Malingering in a correctional setting: The use of the structured interview of reported symptoms in a jail sample. *Behavioral Sciences & The Law*, 27(5), 753–65. <https://doi.org/10.1002/bsl.892>
- McKnight, W. (2016, October 28). *Reframing views of patients who malingering advised*. *Clinical Psychiatry News*. <https://www.mdedge.com/psychiatry/article/116674/practice-management/reframing-views-patients-who-malinger-advised>
- Meadows, L. M. & Morse, J. M. (2001). Constructing evidence within the qualitative project. In J.M. Morse, J.M. Swanson, & A.J. Kuzel (Eds.). *The Nature of Qualitative Evidence* (pp. 188-201). SAGE Publications. <https://dx.doi.org/10.4135/9781412986236.n8>
- McCarthy-Jones, S. & Resnick, P. (2013). Listening to voices: The use of phenomenology to differentiate malingering from genuine auditory verbal hallucinations. *International Journal of Law and Psychiatry*, 37(2), 183-189. <https://doi.org/10.1016/j.ijlp.2013.11.004>
- Millstein S. G. (1996). Utility of the theories of reasoned action and planned behavior for predicting physician behavior: A prospective analysis. *Health Psychology*, 15(5), 398–402. <https://doi.org/10.1037//0278-6133.15.5.398>
- Mittenberg, W., Patton, C., Canyock, E. M., & Condit, D. C. (2002). Base rates of malingering and symptom exaggeration. *Journal of Clinical and Experimental Neuropsychology*, 24(8), 1094–1102. <https://doi.org/10.1076/jcen.24.8.1094.8379>
- Moustakas, C. (1994). *Phenomenological research methods*. SAGE.
- Murdach, A.D. (2006). Social work and malingering. *Health & Social Work*, 31(2), 155-158. <https://doi.org/10.1093/hsw/31.2.155>
- NASW. (2016). NASW standards for social work practice in healthcare settings. <https://www.socialworkers.org/LinkClick.aspx?fileticket=fFnsRHX-4HE%3d&portalid=0>
- NASW. (n.d.). Read the code of ethics. <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
- Pasha, A.K. & Sharma, M. (2019). Malingering, conversion, and factitious disorders. The emotional and monetary costs to the healthcare delivery system. *Journal of Community Hospital Internal Medicine Perspectives*, 9(4), 369-370. <https://doi.org/10.1080/20009666.2019.1643221>

- Perkins, M.B., Jensen, P.S., Jaccard, J., Gollwitzer, P., Oettingen, G., Pappadopulos, E., & Hoagwood, K.E. (2007). Applying theory driven approaches to understanding and modifying clinicians' behavior: What do we know? *Psychiatric Services*, 58(3), 342-348. <https://doi.org/10.1176/ps.2007.58.3.342>
- Reznek L. (1998). On the epistemology of mental illness. *History and Philosophy of the Life Sciences*, 20(2), 215–232. <https://www.jstor.org/stable/23332102>
- Reznek L. (2005). The Rey 15-item memory test for malingering: A meta-analysis. *Brain Injury*, 19(7), 539–543. <https://doi.org/10.1080/02699050400005242>
- Rogers, R., & Bender, S. D. (2003). Evaluation of malingering and deception. In A. M. Goldstein (Ed.), *Handbook of Psychology: Forensic Psychology, Vol. 11*, pp. 109–129. John Wiley & Sons, Inc.
- Rogers, R., Vitacco, M. J., & Kurus, S. J. (2010). Assessment of malingering with repeat forensic evaluations: Patient variability and possible misclassification on the SIRS and other feigning measures. *The Journal of the American Academy of Psychiatry and the Law*, 38(1), 109–114.
- Rumschik, S.M. & Appel, J.M. (2018). Malingering in the psychiatric emergency department: Prevalence, predictors, and outcomes. *Psychiatric Services*, 70(2). <https://www.ncbi.nlm.nih.gov/pubmed/30526343>
- Saldana, J. (2016). *The coding manual for qualitative researchers*. SAGE.
- The United States Department of Justice. (n.d.). *The False Claims Act*. <https://www.justice.gov/civil/false-claims-act>
- Thompson-Leduc, P., Clayman, M. L., Turcotte, S., & Légaré F. (2015). Shared decision-making behaviors in health professionals: A systematic review of studies based on the theory of planned behavior. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 18(5), 754–74. <https://doi.org/10.1111/hex.12176>
- Turner, S. G., & Maschi, T. M. (2015). Feminist and empowerment theory and social work practice. *Journal of Social Work Practice*, 29(2), 151–162. <https://doi.org/10.1080/02650533.2014.941282>
- Velsor, S., & Rogers, R. (2019). Differentiating factitious psychological presentations from malingering: Implications for forensic practice. *Behavioral Sciences & the Law*, 37(1), 1–15. <https://doi.org/10.1002/bsl.2365>
- Waite, S. & Geddes, A. (2006). Malingered psychosis leading to involuntary psychiatric hospitalization. *Australasian Psychiatry*, 14(4). <https://doi.org/10.1111/j.1440-1665.2006.02317.x>
- Walczyk, J., Sewell, N., & DiBenedetto, M. (2018). A review of approaches to detecting malingering in forensic contexts and promising cognitive load-inducing lie detection techniques. *Frontiers in Psychiatry*, 9, 700-700. <https://doi.org/10.3389/fpsy.2018.00700>
- Weiss, K.C. & Van Dell, L. (2017). Liability for diagnosing malingering. *Journal of the American Academy of Psychiatry and the Law Online*, 45(3), 339-347. <http://jaapl.org/content/45/3/339>
- Zubera, Raza, Holaday, & Aggarwal. (2014). Screening for malingering in the emergency department. *Academic Psychiatry*, 39(2). https://www.researchgate.net/publication/269170336_Screening_for_Malingering_in_the_Emergency_Department

April C. Bowie-Viverette, MSW, MBA is currently a second year PhD Social Work at Our Lady of the Lake University. She earned her BS in Psychology from the Jackson State University, her MSW from University of Houston, and her MBA from Texas Woman's University. Her research interests include: integrated healthcare; healthcare utilization; technology in healthcare; and, program development and evaluation.

Towards an Intersectional Intervention for LGBT People with Disabilities

Rachel Womack, MSW, CSW

University of Kentucky, College of Social Work

Correspondence concerning this article should be addressed to Rachel Womack, 619 Patterson Office Tower, Lexington, KY 40506. Email: rpwo222@uky.edu

Abstract

Individuals with disabilities and individuals who identify as LGBT (LGBTPWD) are well known to the field of social work as members of marginalized communities. However, there is a paucity of research examining the intersectionality of these two identities and pertinent considerations for practitioners serving patients who are members of both populations. The research that does exist suggests disability, sexual orientation, and gender identity are intimately connected, and LGBT people with disabilities experience higher rates of several mental health problems including depression, anxiety, PTSD, and other diagnoses. These issues are compounded by a prevalence of stereotypes and a lack of provider competency on issues specific to this population. This paper utilizes an intersectionality framework to describe the unique mental health considerations that arise as a result of multiple identities for individuals living in the United States who have disabilities and identify as LGBT, as well as key challenges for mental health practitioners serving this population. Additionally, this paper outlines one potential intervention for use with LGBTPWD.

Keywords: disability; LGBT; mental health; intersectionality; support groups

Towards an Intersectional Intervention for LGBT People with Disabilities

In October 2020, Texas' social work regulatory board voted to remove disability, gender identity, and sexual orientation from the list of groups protected from discrimination by the board's code of conduct (NASW Texas Chapter, 2020). The Executive Director of NASW/TX released a statement expressing his concern that these changes may deter clients from partaking in social work services or that social workers may now feel emboldened to deny services to certain groups of people even if the ethical obligation to serve these groups remains (Francis, 2020). While this measure has since been reversed by the state's social work board following an outcry by social workers and community members, developments such as this point to a need for increased focus on social work's role in protecting marginalized populations including sexual and gender minorities and people with disabilities, especially in the sphere of mental health therapies and social work practice.

Moving forward, it is imperative that the social work profession strive to not only improve outcomes for the disabled and LGBT populations separately but also to consider the needs of LGBT individuals who are disabled (LGBTPWD). Future research and practice should consider the role intersectionality plays in the experiences of those who meet criteria for inclusion in both groups. This paper attempts to help forge this connection by utilizing an intersectionality framework to describe the unique mental health considerations that arise as a result of multiple minority identities for individuals living in the United States who have disabilities and identify as LGBT, as well as key challenges for mental health practitioners serving this population. Additionally, I suggest a potential intervention for providers who wish to address the problems faced by this population through an intersectional lens.

For the purposes of this discussion, “individuals with disabilities” refers to those living with intellectual or developmental disabilities, which were defined broadly by Carulla and colleagues (2011) as “a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills” (p. 177). Developmental disabilities occur at birth or during the developmental period and can include either intellectual or physical disabilities or both (Thompson Policy Institute, 2016). It is important to note that while the “intellectual and developmental disability population” (IDD) is often discussed as a singular community, intellectual and developmental disability are distinct concepts (Family Service Foundation, 2016). According to the Thompson Policy Institute (2016), intellectual disabilities can fall under the umbrella of developmental disabilities, meaning a person with a developmental disability may or may not meet the criteria for having an intellectual disability. Alternately, a person with an intellectual disability, depending on at what point in the person’s life the disability developed, may or may not qualify as having a developmental disability.

It should be noted that people with intellectual and developmental disabilities are significantly more likely to also experience a physical disability compared to the general population (Hughes-McCormack et al., 2017). Additionally, it is vital to understand the distinction between mental illness and intellectual or developmental disability. While these terms may occasionally be used interchangeably, they are distinct phenomena (Thompson Policy Institute, 2016). Intellectual and developmental disabilities can both alter cognitive ability, but mental illness generally does not diminish cognitive ability. Additionally, while mental illness is typically considered to be pathological, some disabilities, such as autism, can be considered to occur as part of the normal variation of human experience. Advocates of this understanding of disability often reject the medical model of disability in favor of a social model (Mulvaney, 2000). This idea has been slower to take hold within the scientific community but is widely discussed in popular media and disability advocacy circles (Endow, 2019; Lewis, 2020; Matthews, 2015; Stevenson, 2015). Queer disabled activist Eli Clare (2001) aptly sums up this concept:

Disability, not defined by our bodies, but rather by the material and social conditions of ableism; not by the need to use a wheelchair, but rather by the stairs that have no accompanying ramp or elevator. Disability activists fiercely declare that it’s not our bodies that need curing. Rather, it is ableism— disability oppression, as reflected in high unemployment rates, lack of access, gawking, substandard education, being forced to live in nursing homes and back rooms, being seen as childlike and asexual— that needs changing (p. 360).

This paper does not distinguish between those with both intellectual or developmental disabilities and a physical disability and those who do not have a physical disability. While the abbreviated term, LGBT, is utilized in this paper, it should be noted that the discussion does refer to all individuals within the LGBTQIA+ community, including but not limited to lesbians, gay men, bisexual, trans, queer or questioning, intersex, and asexual individuals (University of California San Francisco (UCSF), n.d.). This paper adopts the definitions of sexual orientation or identity and gender identity offered by the Human Rights Campaign (n.d.), with sexual orientation being defined as an enduring romantic or sexual

attraction to others and gender identity being defined as one's concept of self as male, female, both or neither.

Existing research suggests disability, sexual orientation, and gender identity are intimately connected. Research shows lesbians and bisexual women are significantly more likely than straight women to experience some form of disability, and the same holds true for gay and bisexual men (Fredriksen-Goldsen et al., 2012). Lesbian, gay, and bisexual adults with disabilities are also more likely to have been born with or acquired their disability at a young age than heterosexual people with disabilities (Fredriksen-Goldsen et al., 2012). Additionally, authors like Walsh et al. (2018) and Jones et al. (2012) continue to confirm a relationship between prevalence of autism spectrum disorder traits and identification as trans or otherwise gender nonconforming.

While recent literature has done much to elucidate problems facing the LGBT and disabled communities separately, the literature devoted to addressing the unique challenges which occur at the intersection of sexual and gender identity and disability status is sparse. However, what we do know suggests LGBT people with disabilities experience several adverse mental health conditions at disproportionately higher rates than the general population. Research shows LGBT people with disabilities experience increased rates of depression, anxiety, psychological distress, self-harm, PTSD, and other psychological problems compared to the general population and to LGBT people without disabilities (Einfeld et al., 2011; Leonard & Mann, 2018). Additionally, this population is exposed to a variety of psychosocial stressors including stigma, minority stress, loneliness, and discrimination, which could contribute to negative mental health outcomes (Dispenza et al., 2019; Leonard & Mann, 2018; Lopez, 2015). In this paper, I utilize an intersectionality framework to assess and describe the unique mental health challenges facing LGBT individuals with disabilities. I also describe considerations for practitioners serving this population and argue these issues are best addressed through culturally competent, intersectional interventions, such as support groups which have been specifically designed for use with this population.

Intersectionality Theory

The term "intersectionality" was first coined in 1989 to help shed light on the intersection of race and sex for Black women (Crenshaw, 1989). Since its inception, intersectionality theory has been used to provide a lens for examining many distinct sets of multiple minority identities. It is concerned with not only the operation of intersecting marginalized identities, but also with how these intersections can lead to the oppression of certain groups (Harrison, 2017). Authors have described social work's relationship with intersectionality in that it provides an analytical approach for understanding the relationships between complex identities and their effects on people's lives (Mattsson, 2014; Mehrotra, 2010). Indeed, there has been substantial discussion of the need for an intersectional approach to the study of and practice with LGBTPWD (Dispenza et al., 2019; Gutmann Kahn & Lindstrom, 2015; Hunter et al., 2020; Toft et al., 2019, 2020). This paper utilizes an intersectional framework to guide the exploration of the mental health challenges facing LGBTPWD and advocates for utilizing an intersectional approach to guide interventions, such as support groups, with this population.

LGBT People with Disabilities

Young Adults and Adolescents

LGBT people with disabilities face a unique and complex set of challenges related to their mental health and wellbeing as well as their access to appropriate and competent help (Brodwin & Frederick, 2010; Hunter et al., 2020; Kattari et al., 2017; Toft et al., 2019, 2020). To help shed light on this issue, authors have attempted to identify reoccurring themes in the ways both mental health practitioners and society in

general view people with disabilities and their sexual and gender identities and expression, and how these views impact LGBTPWD.

Young adults who identify as LGBTPWD were able to describe several themes involving their perception of how they are seen by society (Toft et al., 2020). The young adults felt they were seen as incapable, immature, and inferior, and there was a pervasive idea among others that they were “going through a phase.” Brodwin and Frederick (2010) showed stereotypes regarding sexuality exist even among people with disabilities who do not identify as a sexual or gender minority, including being viewed as not sexually attractive or incapable of having sexual desires or any type of appropriate, consensual sexual contact. Additionally, Burns and Davies (2011) identified a prevalence of homophobic attitudes among women with intellectual disabilities.

This population may also be at an increased risk of being stereotyped and discriminated against starting from a young age, according to one study (Blyth & Carson, 2007). Adolescent LGBTPWD interviewed in one study reported they had trouble finding safe spaces where they felt supported in all of their identities, and often did what they could to pass as non-queer and non-disabled (Gutmann Kahn & Lindstrom, 2015). Similarly, another study found students with disabilities who are LGBT in university settings may feel a lack of support from university personnel and may feel uncomfortable discussing their identities with others within the university (Henry et al., 2010). Unfortunately, others have also found discrimination against LGBTPWD may exist within both the disabled and LGBT communities, and these issues do not always seem to resolve when LGBTPWD reach adulthood (Lee & Fenge, 2016; Leonard & Mann, 2018).

Intersex Individuals

Further, it has been suggested that intersex individuals with disabilities experience their own unique challenges at the intersection of their identities (Carpenter, 2020). Intersex Human Rights Australia (IHRA) acknowledges that, while intersex and disability rights organizations have a long history of cooperation, the intersectionality of these two identities is poorly recognized within the scientific community (IHRA, 2012). One notable difference that may lead to a different experience in intersex and disabled individuals versus LGBTPWD more generally is the fact that, while belonging to most other sexual and gender minority groups is no longer formally pathologized (Drescher, 2015), belonging to the intersex community is still regarded as a disorder of sexual development (Carpenter, 2018). This attitude toward intersex individuals may further increase the stigma faced by LGBTPWD.

Asexual Individuals

Given the stereotype that individuals with disabilities, regardless of sexual orientation and gender identity, are generally not interested in or not capable of consensual sexual relationships (Brodwin & Frederick, 2010), asexual individuals with disabilities may also be disproportionately impacted by adverse experiences surrounding their identity. Cuthbert (2017) conducted an exploration of the intersection of asexuality and disability. Cuthbert interviewed 11 participants who identified as asexual and disabled, and found all interviewees felt their disability somehow mediated their experience of asexuality. Some individuals noted that since their disabled experience tended to be seen as pathological, others viewed their asexuality as a part of their disability rather than a distinct and enduring sexual orientation. One participant, who identified as asexual and heteroromantic, reported experiencing feelings that his disability defined his whole existence and others tended to be skeptical of the validity of his asexuality.

Other Challenges Related to Dual Identities

Other research has shown exposure to microaggressions, which are brief statements or behaviors that insult someone based on their membership in a group (Pierce et al., 1978), as a form of discrimination can also be detrimental to this population. One study found a greater number of ableist microaggressions are associated with less satisfaction with social supports among LGBTPWD. Additionally, experiencing more microaggressions was associated with a greater level of depressive symptoms (Conover & Israel, 2019).

Hillier and colleagues (2019) further discussed the impact of these dual identities. The researchers found that among a group of individuals with Autism Spectrum Disorder (American Psychiatric Association, 2013) who had differing gender identities, there was a general consensus surrounding a feeling of isolation caused by a lack of understanding of their dual identities as both disabled and gender diverse persons, and the idea that there is a lack of knowledgeable and safe services available to them. This corroborates other findings, which suggest LGBTPWD face decreased access to appropriate social and mental health services, and existing disability-focused services may do a poor job of addressing sexual and gender identity rights and freedoms (Leonard & Mann, 2018).

The aforementioned concept of accessibility is a frequently occurring theme in the literature surrounding issues facing LGBTPWD. Several factors contribute to this lack of accessibility, including physical barriers (Iezzoni, 2011; Hunt et al., 2006); absence of universal design structures and methods (Kattari et al., 2017); and limited practitioner competence and training (Hinde & Mason, 2020; Werner & Stawski, 2012). Hunt and colleagues (2006) conducted interviews with a sample of 25 lesbians with disabilities to gauge their experiences of receiving mental health counseling. A large percentage of study participants expressed their concern at a lack of cultural competence among their mental health providers. Participants also cited a lack of access to the counseling offices themselves, with one individual reporting it was difficult to find a counseling office with a ramp, and once she found one, the door at the top of the ramped entrance was always locked. According to other authors, LGBT people with autism may be especially impacted by a lack of access to appropriate services, with survey respondents citing inappropriate care, refusal of care, and inadequate health insurance coverage as barriers to access (Hall et al., 2020).

Restrictions related to the living environments of LGBTPWD may also negatively impact their sexual health, expression of identity, and safety (McClelland et al, 2012). Alternately, research has shown positive sexual experiences and good sexual health contribute to physical, mental, emotional, and social wellbeing (Hensel, Nance, & Fortenberry, 2016). Respondents to a 2012 survey reported they were affected by rules that restricted their sexual activity, especially if they lived with their parents or in a group setting (McClelland et al., 2012). This led to some of the respondents resorting to the use of unsafe or risky social spaces for sexual encounters.

Role of Intersectionality and Considerations for Social Workers and Mental Health Providers

This section will focus on the importance of utilizing an intersectional framework and strategies that promote resilience in social work practice with this population. According to Johnson (n.d.), resilience is the ability to recover from adverse experiences. Johnson goes on to describe resilience as an important foundation for healing trauma and overcoming individual and systemic sources of stress. This topic has been discussed on a broad scale for its applicability to therapeutic approaches in general. Incorporating an intersectional framework for social work practice was discussed by Mattsson (2014). Mattsson suggested social workers take time to critically reflect on the power relations at play between the social worker, client, and social work organization while paying special attention to gender, sexuality, race, and class as central to oppression. In a discussion of techniques for the ethical application of art therapy, Kuri (2017) asserted that an intersectional framework should be incorporated whenever possible to address cultural disadvantage. Kuri described a need for therapists to “make a commitment to ongoing reflexivity, which

means working toward a critical awareness of their social location and assumptions with respect to power, privilege, and oppression” (p. 120).

Utilizing an intersectional approach to practice has also been discussed in the context of more specific populations. Authors like Golden and Oransky (2019) described the significance of viewing a population of transgender adolescents through an intersectional lens and conducting therapy with them accordingly. The authors theorized there are four central tenets of intersectionality for use in therapy. First, the practitioner must acknowledge that individuals may hold many identities at the same time, and the combination of those identities shapes experience. Second, the practitioner must understand identities are not uniform and identities and their relationships can change over time. Third, it should be understood that not all individuals under the umbrella of a certain identity will hold the same history or experience. Finally, it is vital to remember the amount of privilege or oppression a person experiences is largely contextual and dependent on the situation.

Hunter et al. (2020) encouraged practitioners to use such an intersectional lens when developing and utilizing treatment models with LGBTPWD specifically. It has also been emphasized that practitioners using intersectional perspectives must seek to understand distinct social identity categories while also understanding the complexities of the ways people perceive their own identities (Miller, 2018). Additionally, utilizing such a framework with goals like improving health equity should focus not only on providing better care and closing health gaps, but on “celebrating difference” (Nakkeeran & Nakkeeran, 2018, p. 17).

Some authors have proposed using an intersectional treatment method that focuses on promoting resilience factors (Hunter et al., 2020; Miller, 2018). In this context, Hunter and colleagues (2020) described resilience as the ability to gain intrapersonal strength in the face of stressors, and they discussed the importance of promoting maximizers of resilience, such as self-acceptance and social support, through treatment. In discussing the promotion of resilience factors in racial/ethnic minorities living with HIV, Earnshaw and colleagues (2015) suggested that using an intersectional approach could allow providers to recognize the way stigma and discrimination relate to a lack of resilience factors in their clients. To combat the impact of this stigma and discrimination, they proposed that interventions take a strengths-based approach focused on increasing acceptance and social supports. In the LGBTPWD population specifically, factors contributing to resilience include self-acceptance, advocacy and social support. Additionally, several factors inhibit resilience, including fragmentation of identity and identity concealment (Hunter et al., 2020).

Other studies have focused on empowerment of these clients and suggested an emphasis on collaboration between practitioner and client and on promoting self-determination, autonomy, and dignity (Dispenza et al., 2019). Similarly, some have argued that since this population might be disempowered in their relationships, empowerment in a counseling setting is especially important (Lopez, 2015). When considering this approach, it is valuable to understand that the concept of empowerment can be seen as both a process and an outcome (Okech et al., 2020). It describes the enabling of marginalized individuals and groups to access resources that increase their strengths and allow them more freedom to actualize their goals and aspirations (Teater, 2014). Therefore, it follows that empowering LGBTPWD to access these strengths (e.g., resilience factors) may help free them to overcome some of the challenges they experience related to their identities.

An additional, and important, aspect of treatment of LGBTPWD through an intersectional lens is affirmation of this population’s multiple identities and the unique set of challenges that may accompany them. The importance of using trans-disability affirming therapeutic techniques with clients who are transgender and disabled has been discussed (Ballan et al., 2011). The benefits of using affirming and strengths-based practice techniques with LGBTPWD have also been described (Gates & Kelly, 2017). Since this population is known to face substantial discrimination and little validation of their identities

(Kattari et al., 2017; Hillier et al., 2019; Lee & Fenge, 2016), it follows that these aspects of treatment may be especially vital. One such intersectional intervention for serving LGBTPWD, the support group, is outlined below.

Role of Race and Age in an Intersectional Treatment Approach

Finally, as an intersectional treatment approach for LGBTPWD must consider the dynamics of power, privilege, and oppression related to *all* aspects of a person's identity, credence should be given to understanding the intersectionality of race and age within the LGBTPWD population. The importance of considering racial background when providing services to LGBTPWD will be discussed first. While there is comparatively little research dedicated to examining the experiences of LGBT people of color with disabilities specifically, the intersection of race and sexual and gender identity has been well explored (Nadal et al., 2017).

Cyrus (2017) discussed multiple minority stress in LGBT people of color, citing that this population is at an increased risk of stigmatization, discrimination, and fear of rejection. Cyrus found LGBT people of color are often subjected to racism and social exclusion from the LGBT community and may experience homophobia from their racial/ethnic group community. It was also theorized that the stressors faced by this population likely have implications regarding risk for mental illness, access to mental healthcare, and competency and quality of care from providers (Cyrus, 2017).

An examination of the existing literature related to the identities and experiences of disabled people of color reveals a whitewashed version of disability studies (Bell, 2010). Further, it has been suggested that for disabled people of color, racial identity development must always occur in the context of disability (Alston et al., 1996). Similarly, Mpofu and Harley (2006) asserted that racial identity development for disabled people of color might be specific to the disability the person experiences. For instance, a blind person may have a vastly different experience about their own race compared to a deaf person. Mpofu and Harley (2006) also suggested that whether a disabled person of color identifies more strongly with their racial identity or their disabled identity may depend on any discrimination or oppression they have faced based on those identities. Therefore, a provider seeking an intersectional approach to treatment with this population should pay special attention to the experiences of the individual surrounding discrimination, power, and oppression, and how these experiences have shaped the person's identity and mental health. Additionally, providers should understand an LGBT disabled person of color's identity and experiences may be different based on the nature of the person's disability and the person's specific sexual and gender identity.

Perhaps unsurprisingly, there is also little existing literature about the role of age in experiences surrounding identity, stigmatization, and mental health issues for LGBTPWD. Since inquiry regarding identity development and expression is often focused in adolescence, there is ample research illustrating adverse events and emotions experienced by LGBT youth with disabilities (e.g., Gutmann Kahn & Lindstrom, 2015). However, other populations, such as LGBT older adults with disabilities, have scarcely been explored.

In a paper describing culturally competent practice with LGBT older adults in general, Fredriksen-Goldsen and colleagues (2014) characterized LGBT older adults as an at-risk population that experiences many aging and health disparities. Additionally, the aging LGBT population faces higher rates of disability and mental health issues compared to the general population of older adults (Fredriksen-Goldsen et al., 2014). Unfortunately, these issues may be exacerbated by the fact that nearly half of gay and bisexual older adult men live alone without access to adequate services (Fredriksen-Goldsen et al., 2014).

Based on the above information, practitioners seeking to support LGBTPWD should consider the age group they serve in working to provide effective and culturally competent services. While providing intersectional treatment to LGBT children and young adults with disabilities, it may be important for the practitioner to consider the roles of belonging, social supports among peers, and parental perceptions of identity. Additionally, it is important to assess the extent and types of services these individuals are receiving or recently received at school, and whether those providers were affirming of their clients' multiple marginalized identities.

Alternately, the provider seeking an intersectional approach to treatment for their LGBT older adult clients with disabilities may need to consider the importance of promoting healthy aging, as well as more specific factors such as an increased risk of HIV/AIDS or trauma related to surviving the AIDS crisis (High et al., 2012). Additionally, since research indicates LGBT older adults are often "invisible" in health services (Brotman et al., 2003), it is important for providers working with this population to understand that their clients may have a mistrust of healthcare systems and may be uncomfortable or unaccustomed to disclosing their identities to practitioners.

Benefits of Support Groups for Marginalized Populations

Support groups have long been utilized as an intervention to help with myriad problems for diverse groups of marginalized individuals. To illustrate this point, a study that focused on the use of support groups to help with resilience, social skills, and overcoming structural barriers in African and Caribbean LGBT individuals found multiple benefits, including self-acceptance, improved mental health, reduced isolation, reduced stigma and discrimination, and fewer issues with structural barriers to success (Logie et al., 2016). Support groups have also been used successfully as an intervention to enhance wellbeing and ameliorate mental health issues in populations ranging from women with postpartum depression (Anderson, 2013) to cancer survivors (Stephen et al., 2014).

A particularly positive and relevant characteristic of support groups for use with marginalized populations is their ability to provide a basis for social support. Group identification, as can be aided by participation in a support group, predicts an increase in social support, higher levels of self-esteem, and resistance to stereotypes (Crabtree et al., 2010). This increased social support in turn can lead to lower levels of depression and higher quality of life overall (Eom et al., 2013).

The utilization of support groups to address individual trauma and stress related to oppression was also discussed by Elligan and Utsey (1999). The authors developed a support group focused on serving Black men who had experienced psychological trauma as a result of living in a racist and oppressive society. All participants reported feeling less anger and frustration, and all participants reported that they gained an increased sense of appreciation for other Black men and felt a sense of belonging within the group.

Support Groups for LGBTPWD

To date, there is relatively little evidence supporting the effectiveness of any one intervention for use with LGBTPWD. However, given data highlighting high rates of depression, anxiety, and other mental health problems (Einfeld et al., 2011; Leonard & Mann, 2018), as well as low levels of social support experienced by this population (Henry et al., 2010), it follows that support groups could be perfectly poised to help alleviate some of these problems. After all, research suggests support groups have been shown to be an especially useful intervention when used for similar issues within other marginalized populations.

Tallentire and colleagues (2020) focused on examining the utility of this intervention for LGBTPWD. A group of LGBTPWD who had attended a support group with an intersectional focus spoke about their

experiences. Participants often reported that coming to the support group was their first experience with “coming out” about their sexual identity, and they associated the time before they were open about their identities with negative emotions. Participants also reported that they felt safe and able to be themselves when they came to the group, and that they felt socially supported by staff and other group participants. Also, many of the people involved in the group stated participation in the support group contributed to a sense of pride in their multiple identities.

An older study examined the efficacy of a psychoeducational support group for men with intellectual disabilities who have sex with men (Withers, 2002). The author found the group in question helped the participants to form positive relationships with their sexual identities and to discuss issues related to safe sex. While these findings are not specifically related to mental health disorders, nurturing a positive relationship with one’s own identity, especially when that identity is as a member of the LGBT population, has been linked with more positive mental health outcomes (Bockting et al., 2013).

The Intersectional Support Group

To best address the unique challenges faced by LBGTPWD, providers must be well-versed in the concept of intersectionality and the use of intersectional approaches in guiding their support group. Luckily, support groups naturally lend themselves to being safe spaces for marginalized individuals who are members of diverse populations (Hartal, 2018; Rier, 2007). Therefore, the burden of creating an environment that honors intersectional identities and fosters building resilience and empowerment lies with the support group facilitator.

According to Mental Health America (2016), the role of a support group facilitator is to guide the group in healthy and beneficial discussion. Facilitators work to ensure a supportive environment, to encourage exploration of emotion and identity, and to provide a model of resiliency. A simple way for facilitators to promote this is by honoring individuals’ pronouns, names, and ways they refer to themselves, including whether they prefer person-first or identity-first language. For instance, an individual who prefers person-first language might feel most comfortable being called a person with autism, whereas someone who prefers identity-first language may prefer being known as an autistic person. They also must accept differences in the identities of their group participants and urge others within the group to do the same. Additionally, facilitators should take care to affirm the identities and experiences of their participants at all times.

Many of the considerations for intersectional practice outlined above can readily translate to use within a support group environment. Consequently, an intersectional approach to treating this population would focus on all aspects of health. The four dimensions of health for LBGTPWD have been described as physical wellness, emotional vitality, functionality, and social engagement (Dispenza et al., 2016). While other research in this particular area is limited, it makes sense that a practical approach to treating the mental health concerns of LBGTPWD would include consideration for pertinent physical, emotional, and social concerns. Importantly, just as physical and mental health are intrinsically linked, so are disability, sexuality, and gender (Toft et al., 2019). In essence, you cannot fully consider the impact of a person’s disability on their life without considering their disability in the context of sexuality and gender. To accomplish this, the support group facilitator can introduce topics to the group that include all dimensions of health. Additionally, the facilitator can encourage the healthy expansion of any discussion centering on physical, emotional, functional, or social health within the LBGTPWD population.

Furthermore, the facilitator of an intersectional support group for LBGTPWD should take ample time to educate themselves on the dynamics of power and oppression that may impact the experiences of their group participants. This is particularly important for the support group leader who is serving LGBT people of color with disabilities (Cyrus, 2017). Ideally, this should be coupled with an effort to spend time following each group session reflecting on the ways stigma and discrimination played out in the

stories of the participants. Then, since factors such as self-acceptance and social support help to build resilience in LGBTPWD (Hunter et al., 2020), the facilitator should help assist individuals in accessing the natural social supports within the group.

A final important consideration for the intersectional support group is accessibility. There is strikingly little literature available surrounding accessibility of mental health services. However, the concept of Universal Design for Learning, which provides flexibility in the way individuals access and engage with material (Morin, n.d.), works well to provide a framework for making services more accessible to all. Making support groups more accessible includes ensuring the physical location of the group is safely reachable and navigable for individuals with physical disabilities (Hunt et al., 2006) and that the location is free of distracting stimuli such as loud noises or other unrelated activity. Online support groups provide one potential solution to this problem, since LGBTPWD could access them from the comfort and safety of their homes. In-person support groups should be situated in quiet, private locations without bright colors, patterns, or fluorescent lights, as these things can contribute to sensory overload in some individuals with disabilities (Bogdashina, 2015).

Conclusion

This paper utilizes an intersectional framework to describe the unique mental health considerations that arise as a result of the multiple identities for individuals living in the United States who have disabilities and identify as LGBT, as well as key challenges for mental health practitioners serving this population. This paper also suggests one plausible intervention, the support group, for use with this population.

The considerations presented above provide useful guidance for social work practitioners who wish to provide compassionate and competent care to LGBTPWD. This population faces several obstacles arising at the intersection of their multiple identities, and social work is perfectly seated to aid in the alleviation of some of these stressors. The need for a more nuanced, culturally competent understanding of LGBTPWD is clear (Dispenza et al., 2016; Lee & Fenge, 2016; McClelland et al., 2012).

I join others (Bernert & Ogletree, 2013; Brodwin & Frederick, 2010; Gutmann Kahn & Lindstrom, 2015; Hunter et al., 2020; Toft et al., 2020) in calling for a deeper level of understanding and education surrounding social work with this population. Sexual and gender minority individuals with disabilities need and deserve to be seen as the unique and complex people they are, and they should be treated through an intersectional lens in such a way that serves to honor and protect their identities while empowering their potential and affirming their sense of autonomy. Support groups offer a useful and viable option as an intervention that can be utilized to address the unique problems which arise at the intersection of disabled and LGBT identities. As the social work profession moves to address the outstanding disparities facing LGBTPWD, care must be taken to create policies and procedures that serve to protect this undoubtedly marginalized population.

References

- Alston, R. J., Bell, T. J., & Feist-Price, S. (1996). Racial identity and African Americans with disabilities: Theoretical and practical considerations. *Journal of Rehabilitation*, 62(2), 11.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Anderson, L. N. (2013). Functions of support group communication for women with postpartum depression: How support groups silence and encourage voices of motherhood. *Journal of Community Psychology*, 41(6), 709-724. <https://doi.org/10.1002/jcop.21566>

- Ballan, M. S., Romanelli, M., & Harper IV, J. N. (2011). The social model: A lens for counseling transgender individuals with disabilities. *Journal of Gay & Lesbian Mental Health, 15*(3), 260-280. <https://doi.org/10.1080/19359705.2011.582073>
- Bell, C. (2010). Is disability studies actually white disability studies? In L.J Davis (Ed.) *The Disability Studies Reader*, pp. 402-410.
- Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research, 57*(3), 240-249. <https://doi.org/10.1111/j.1365-2788.2011.01529.x>
- Blyth, C., & Carson, I. (2007). Sexual uncertainties and disabled young men: Silencing difference within the classroom. *Pastoral Care, 25*, 34–38. <https://doi.org/10.1111/j.1468-0122.2007.00414.x>
- Bockting, W. O., Miner, M. H., Swinburne Romine, R. E., Hamilton, A., & Coleman, E. (2013). Stigma, mental health, and resilience in an online sample of the US transgender population. *American Journal of Public Health, 103*(5), 943-951. <https://doi.org/10.2105/ajph.2013.301241>
- Bogdashina, O. (2015). *Sensory intolerance in autism*. The Voice. <https://www.integratedtreatmentservices.co.uk/blog/sensory-intolerance-in-autism/>
- Brodwin, M. G., & Frederick, P. C. (2010). Sexuality and societal beliefs regarding persons living with disabilities. *Journal of Rehabilitation, 76*(4), 37.
- Brotman, S., Ryan, B., & Cormier, R. (2003). The health and social service needs of gay and lesbian elders and their families in Canada. *The Gerontologist, 43*(2), 192-202. <https://doi.org/10.1093/geront/43.2.192>
- Burns, J., & Davies, D. (2011). Same-sex relationships and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(4), 351-360. <https://doi.org/10.1111/j.1468-3148.2010.00609.x>
- Carpenter, M. (2018). Intersex variations, human rights, and the International classification of diseases. *Health and Human rights, 20*(2), 205.
- Carulla, L. S., Reed, G. M., Vaez-Azizi, L. M., Cooper, S. A., Leal, R. M., Bertelli, M., Adnams, C., Cooray, S., Deb, S., Dirani, L., Girimaji, S., Katz, G., Kwok, H., Luckasson, R., Simeonsson, R., Walsh, C., Munir, K., & Saxena, S. (2011). Intellectual developmental disorders: Towards a new name, definition and framework for “mental retardation/intellectual disability” in ICD-11. *World Psychiatry, 10*(3), 175. <https://doi.org/10.1002/j.2051-5545.2011.tb00045.x>
- Clare, E. (2001). Stolen bodies, reclaimed bodies: Disability and queerness. *Public Culture, 13*(3), 359-365. <https://doi.org/10.1215/08992363-13-3-359>
- Conover, K. J., & Israel, T. (2019). Microaggressions and social support among sexual minorities with physical disabilities. *Rehabilitation Psychology, 64*(2), 167. <https://doi.org/10.1037/rep0000250>
- Crabtree, J. W., Haslam, S. A., Postmes, T., & Haslam, C. (2010). Mental health support groups, stigma, and self-esteem: Positive and negative implications of group identification. *Journal of Social Issues, 66*(3), 553-569. <https://doi.org/10.1111/j.1540-4560.2010.01662.x>
- Crenshaw, K. (1989). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review, 43*, 1241. <https://www.jstor.org/stable/1229039>
- Cuthbert, K. (2017). You have to be normal to be abnormal: An empirically grounded exploration of the intersection of asexuality and disability. *Sociology, 51*(2), 241-257. <https://doi.org/10.1177/0038038515587639>
- Cyrus, K. (2017). Multiple minorities as multiply marginalized: Applying the minority stress theory to LGBTQ people of color. *Journal of Gay & Lesbian Mental Health, 21*(3), 194-202. <https://doi.org/10.1080/19359705.2017.1320739>
- Dispenza, F., Harper, L. S., & Harrigan, M. A. (2016). Subjective health among LGBT persons living with disabilities: A qualitative content analysis. *Rehabilitation Psychology, 61*(3), 251. <https://doi.org/10.1037/rep0000086>
- Dispenza, F., Brennaman, C., Harper, L. S., Harrigan, M. A., Chastain, T. E., & Procter, J. E. (2019). Career development of sexual and gender minority persons living with disabilities. *The Counseling Psychologist, 47*(1), 98-128. <https://doi.org/10.1177/0011000018819425>

- Drescher, J. (2015). Out of DSM: Depathologizing homosexuality. *Behavioral Sciences*, 5(4), 565-575. <https://doi.org/10.3390/bs5040565>
- Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2015). Stigma and racial/ethnic HIV disparities: Moving toward resilience. *Stigma and Health*, 1(S), 60–74. <https://doi.org/10.1037/2376-6972.1.S.60>
- Elligan, D., & Utsey, S. (1999). Utility of an African-centered support group for African American men confronting societal racism and oppression. *Cultural Diversity and Ethnic Minority Psychology*, 5(2), 156. <https://doi.org/10.1037/1099-9809.5.2.156>
- Einfeld S. L., Ellis L. A. & Emerson E. (2011) Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. *Journal of Intellectual & Developmental Disability* 36, 137–143. <https://doi.org/10.1080/13668250.2011.572548>
- Endow, J. (2019). *Is autism a disability or a difference?* Ollibean. <https://ollibean.com/autism-disability-difference/>
- Eom, C. S., Shin, D. W., Kim, S. Y., Yang, H. K., Jo, H. S., Kweon, S. S., Kang, Y. S., Kim, J. H., Cho, B. L., & Park, J. H. (2013). Impact of perceived social support on the mental health and health-related quality of life in cancer patients: results from a nationwide, multicenter survey in South Korea. *Psycho-Oncology*, 22(6), 1283-1290. <https://doi.org/10.1002/pon.3133>
- Family Service Foundation. (2016). *The difference between intellectual and developmental disabilities*. <https://www.fsfinc.org/blog/fsf-blog/the-difference-between-an-intellectual-and-developmental-disability#:~:text=There%20are%20many%20different%20terms,they%20are%20not%20the%20same>
- Francis, W. (2020, October). *Statement by the Texas Chapter of the National Association of Social Workers in response to the Texas State Board of Social Worker Examiners change to the Social Work Code of Conduct*. NASW/TX. https://cdn.ymaws.com/www.naswtx.org/resource/resmgr/Statement_10.15.2020.pdf
- Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emler, C. A., & Hooyman, N. R. (2014). Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of Gerontological Social Work*, 57(2-4), 80-107. <https://doi.org/10.1080/01634372.2014.890690>
- Fredriksen-Goldsen, K. I., Kim, H. J., & Barkan, S. E. (2012). Disability among lesbian, gay, and bisexual adults: Disparities in prevalence and risk. *American Journal of Public Health*, 102(1), e16-e21. <https://doi.org/10.2105/AJPH.2011.300379>
- Gates, T. G., & Kelly, B. L. (2017). Affirming and strengths-based models of practice. In M. P. Dentato (Ed.), *Social Work Practice with the LGBTQ Community: The Intersection of History, Health, Mental Health, and Policy Factors*, pp. 235-248. https://ecommons.luc.edu/cgi/viewcontent.cgi?article=1091&context=socialwork_facpubs
- Golden, R. L., & Oransky, M. (2019). An intersectional approach to therapy with transgender adolescents and their families. *Archives of Sexual Behavior*, 48(7), 2011-2025. <https://doi.org/10.1007/s10508-018-1354-9>
- Gutmann Kahn, L., & Lindstrom, L. (2015, October). “I just want to be myself”: Adolescents with disabilities who identify as a sexual or gender minority. *The Educational Forum*, 79(4), 362-376. <https://doi.org/10.1080/00131725.2015.1068416>
- Hall, J. P., Batza, K., Streed, C. G., Boyd, B. A., & Kurth, N. K. (2020). Health disparities among sexual and gender minorities with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-7. <https://doi.org/10.1007/s10803-020-04399-2>
- Harrison, L. (2017). Redefining intersectionality theory through the lens of African American young adolescent girls’ racialized experiences. *Youth & Society*, 49(8), 1023-1039. <https://doi.org/10.1177/0044118X15569216>
- Hartal, G. (2018). Fragile subjectivities: Constructing queer safe spaces. *Social & Cultural Geography*, 19(8), 1053-1072. <https://doi.org/10.1080/14649365.2017.1335877>

- Henry, W. J., Fuerth, K., & Figliozzi, J. (2010). Gay with a disability: A college student's multiple cultural journey. *College Student Journal*, 44(2).
- Hensel, D. J., Nance, J., & Fortenberry, J. D. (2016). The association between sexual health and physical, mental, and social health in adolescent women. *Journal of Adolescent Health*, 59(4), 416-421. <https://doi.org/10.1016/j.jadohealth.2016.06.003>
- High, K. P., Brennan-Ing, M., Clifford, D. B., Cohen, M. H., Currier, J., Deeks, S. G., & Volberding, P. (2012). HIV and aging: State of knowledge and areas of critical need for research. A report to the NIH Office of AIDS Research by the HIV and Aging Working Group. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 60, S1-S18. <https://doi.org/10.1097/qai.0b013e31825a3668>
- Hillier, A., Gallop, N., Mendes, E., Tellez, D., Buckingham, A., Nizami, A., & O'Toole, D. (2019). LGBTQ+ and autism spectrum disorder: Experiences and challenges. *International Journal of Transgender Health*, 21(1), 98-110. <https://doi.org/10.1080/15532739.2019.1594484>
- Hinde, K., & Mason, J. (2020). Health practitioner knowledge and confidence in diagnosis and treatment of mental health issues in people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 45(3), 269-278. <https://doi.org/10.3109/13668250.2020.1730075>
- Hughes-McCormack, L. A., Rydzewska, E., Henderson, A., MacIntyre, C., Rintoul, J., & Cooper, S. A. (2017). Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open*, 3(5), 243-248. <https://doi.org/10.1192/bjpo.bp.117.005462>
- Human Rights Campaign. (n.d.). *Sexual orientation and gender identity definitions*. <https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions>
- Hunt, B., Matthews, C., Milsom, A., & Lammel, J. A. (2006). Lesbians with physical disabilities: A qualitative study of their experiences with counseling. *Journal of Counseling & Development*, 84(2), 163-173. <https://doi.org/10.1002/j.1556-6678.2006.tb00392.x>
- Hunter, T., Dispenza, F., Huffstead, M., Suttles, M., & Bradley, Z. (2020). Queering disability: Exploring the resilience of sexual and gender minority persons living with disabilities. *Rehabilitation Counseling Bulletin*, 64(1), 31-41. <https://doi.org/10.1177/0034355219895813>
- Iezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30(10), 1947-1954. <https://doi.org/10.1377/hlthaff.2011.0613>
- Intersex Human Rights Australia. (2012, October 29). *Intersex: Intersectionalities with disabled people*. <https://ihra.org.au/21214/intersex-and-disability/>
- Johnson, K. (n.d.). Behavioral health brief: Enhancing trauma-informed approaches and resilience. *Social Work Today*, 17(6), 32. <https://www.socialworktoday.com/archive/ND17p32.shtml>
- Jones, R. M., Wheelwright, S., Farrell, K., Martin, E., Green, R., Di Ceglie, D., & Baron-Cohen, S. (2012). Brief report: Female-to-male transsexual people and autistic traits. *Journal of Autism and Developmental Disorders*, 42(2), 301-306. <https://doi.org/10.1007/s10803-011-1227-8>
- Kattari, S. K., Walls, N. E., & Speer, S. R. (2017). Differences in experiences of discrimination in accessing social services among transgender/gender nonconforming individuals by (Dis)ability. *Journal of Social Work in Disability & Rehabilitation*, 16(2), 116-140. <https://doi.org/10.1080/1536710X.2017.1299661>
- Kuri, E. (2017). Toward an ethical application of intersectionality in art therapy. *Art Therapy*, 34(3), 118-122. <https://doi.org/10.1080/07421656.2017.1358023>
- Lee, S., & Fenge, L. (2016). Sexual well-being and physical disability. *The British Journal of Social Work*, 46(8), 2263-2281. <https://doi.org/10.1093/bjsw/bcw107>
- Leonard, W., & Mann, R. (2018). The everyday experiences of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability. *Analysis & Policy Observatory*, 111. <https://www.rainbowhealthvic.org.au/media/pages/research-resources/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability/1242611313-1605661766/the-everyday-experiences-of-lesbian-gay-bisexual-transge>
- Lewis, K. (2020). *Autism is an identity, not a disease: Inside the neurodiversity movement*. Elemental. <https://elemental.medium.com/autism-is-an-identity-not-a-disease-inside-the-neurodiversity-movement-998ecc0584cd>

- Logie, C. H., Lacombe-Duncan, A., Lee-Foon, N., Ryan, S., & Ramsay, H. (2016). "It's for us—newcomers, LGBTQ persons, and HIV-positive persons. You feel free to be": A qualitative study exploring social support group participation among African and Caribbean lesbian, gay, bisexual and transgender newcomers and refugees in Toronto, Canada. *BMC International Health and Human Rights*, 16(1), 1-10. <https://doi.org/10.1186/s12914-016-0092-0>
- Lopez, M. (2015). Developmental disability, sexuality, and counseling: A call for action and ecological implications. *Journal of the Pennsylvania Counseling Association*, 14, 19-27. https://associationdatabase.com/aws/PACA/asset_manager/get_file/102307?ver=50
- Matthews, D. (2015). *We've called autism a disease for decades. We were wrong.* Vox. <https://www.vox.com/2015/8/31/9233295/autism-rights-kanner-asperger>
- Mattsson, T. (2014). Intersectionality as a useful tool: Anti-oppressive social work and critical reflection. *Affilia*, 29(1), 8-17. <https://doi.org/10.1177/0886109913510659>
- McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., Marshall, Z., Travers, R., & Proudfoot, D. (2012). Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, 59(6), 808-819. <https://doi.org/10.1080/00918369.2012.694760>
- Mental Health America. (2016). *Support group facilitation guide.* <https://www.mhanational.org/sites/default/files/MHA%20Support%20Group%20Facilitation%20Guide%202016.pdf>
- Mehrotra, G. (2010). Toward a continuum of intersectionality theorizing for feminist social work scholarship. *Affilia*, 25(4), 417-430. <https://doi.org/10.1177/0886109910384190>
- Miller, R. A. (2018). Toward intersectional identity perspectives on disability and LGBTQ identities in higher education. *Journal of College Student Development*, 59(3), 327-346. <https://doi.org/10.1353/csd.2018.0030>
- Morin, A. (n.d.). *What is Universal Design for Learning (UDL)?* <https://www.understood.org/en/learning-thinking-differences/treatments-approaches/educational-strategies/universal-design-for-learning-what-it-is-and-how-it-works>
- Mpofu, E., & Harley, D. A. (2006). Racial and disability identity: Implications for the career counseling of African Americans with disabilities. *Rehabilitation Counseling Bulletin*, 50(1), 14-23. <https://doi.org/10.1177/00343552060500010301>
- Mulvany, J. (2000). Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health & Illness*, 22(5), 582-601. <https://doi.org/10.1111/1467-9566.00221>
- Nadal, K. L., Erazo, T., Schulman, J., Han, H., Deutsch, T., Ruth, R., & Santacruz, E. (2017). Caught at the intersections: Microaggressions toward lesbian, gay, bisexual, transgender, and queer people of color. In R. Ruth & E. Santacruz (Eds.), *LGBT psychology and mental health: Emerging research and advances*, 133-152.
- Nakkeeran, N., & Nakkeeran, B. (2018). Disability, mental health, sexual orientation and gender identity: understanding health inequity through experience and difference. *Health Research Policy and Systems*, 16(1), 97. <https://doi.org/10.1186/s12961-018-0366-1>

- NASW, Texas Chapter. (2020, October 16). *NASW/TX statement on new TSBSWE ruling- Code of conduct*. <https://www.naswtx.org/page/conductruling>
- Okech, V., Neszméry, Š., & Mačkinová, M. (2020). Empowering the marginalized through community work: A Literature review. *Proceedings of CBU in Social Sciences, 1*, 173-178. <https://doi.org/10.12955/pss.v1.67>
- Pierce, C., Carew, J., Pierce-Gonzalez, D., & Willis, D. (1978). An experiment in racism: TV commercials. In C. Pierce (Ed.), *Television and education* (pp. 62–88). Beverly Hills, CA: Sage
- Rier, D. A. (2007). Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. *Sociology of Health & Illness, 29*(7), 1043-1058. <https://doi.org/10.1111/j.1467-9566.2007.01023.x>
- Stephen, J., Collie, K., McLeod, D., Rojubally, A., Fergus, K., Specca, M., ... & Elramly, M. (2014). Talking with text: Communication in therapist-led, live chat cancer support groups. *Social Science & Medicine, 104*, 178-186. <https://doi.org/10.1016/j.socscimed.2013.12.001>
- Stevenson, N. (2015). *Autism doesn't have to be viewed as a disability or disorder*. The Guardian. <https://www.theguardian.com/science/blog/2015/jul/16/autism-doesnt-have-to-be-viewed-as-a-disability-or-disorder>
- Tallentire, L., Smith, M., David, L., Roberts, A., Morrow, S., Withers, P., & Smith, I. (2020). Stories of people who have attended a lesbian, gay, bisexual and trans support group in a secure intellectual disability service. *Journal of Applied Research in Intellectual Disabilities, 33*(1), 17-28. <https://doi.org/10.1111/jar.12281>
- Teater, B. (2014). *An introduction to applying social work theories and methods*. Berkshire: Open University Press.
- Thompson Policy Institute. (2016). *Comparing mental illness and intellectual and developmental disabilities*. Chapman University. <https://blogs.chapman.edu/tpi/2016/08/02/comparing-mental-illness-and-intellectual-and-developmental-disabilities/>
- Toft, A., Franklin, A., & Langley, E. (2019). Young disabled and LGBT+: Negotiating identity. *Journal of LGBT Youth, 16*(2), 157-172. <https://doi.org/10.1080/19361653.2018.1544532>
- Toft, A., Franklin, A., & Langley, E. (2020). 'You're not sure that you are gay yet': The perpetuation of the 'phase' in the lives of young disabled LGBT+ people. *Sexualities, 23*(4), 516-529. <https://doi.org/10.1177/1363460719842135>
- University of California San Francisco (UCSF). (n.d.). *Lesbian, gay, bisexual and transgender resource center*. <https://lgbt.ucsf.edu/glossary-terms>
- Walsh, R. J., Krabbendam, L., Dewinter, J., & Begeer, S. (2018). Brief report: Gender identity differences in autistic adults: Associations with perceptual and socio-cognitive profiles. *Journal of Autism and Developmental Disorders, 48*(12), 4070-4078. <https://doi.org/10.1007/s10803-018-3702-y>
- Werner, S., & Stawski, M. (2012). Mental health: Knowledge, attitudes and training of professionals on dual diagnosis of intellectual disability and psychiatric disorder. *Journal of Intellectual Disability Research, 56*(3), 291-304. <https://doi.org/10.1111/j.1365-2788.2011.01429.x>
- Withers, P. (2002). A psychoeducational group for men with intellectual disabilities who have sex with men. *Journal of Applied Research in Intellectual Disabilities, 14*(4), 327-329. <https://doi.org/10.1111/jar.12038>

Rachel Womack, MSW, CSW is a second year PhD student in the College of Social Work at the University of Kentucky. Rachel is a research assistant in the college's Self-Care Lab and supervises an IPS Supported Employment program for individuals with disabilities at a local nonprofit. Rachel is committed to furthering rights and opportunities for members of the LGBTQIA+ and disabled communities.

Centering Autistic Persons' Perspectives in Autism Social Policy: A Qualitative Study

Margaret G. Janse van Rensburg, MSW, RSW

Carleton University, School of Social Work

Correspondence concerning this article should be addressed to Margaret Janse van Rensburg, Carleton University, 1125 Colonel By Dr, Ottawa, ON K1S 5B6. Email: margaretjansevanrens@cmail.carleton.ca

Abstract

Ontario overhauled its autism program in 2019 seeking to replace a child-centred direct service or funding program with a cash-based benefit called the Childhood Budgets program. However, this program development did not reflect the opinions of autistic persons. Using principles of grounded theory and participatory action research, a structural social work and critical autism studies lens, this research draws from one-to-one interviews with four autistic adults in Ottawa, Ontario asking autistic adults their perspectives of autism funding in Ontario. Participants emphasized autistic identity, areas of support improvement, systemic inadequacies in education and medical settings, and avenues for inclusive policy creation. Bringing the perspectives of autistic adults, who are often excluded from conversations about autism policy, this research demonstrates autistic adults in Ontario hold diverse perspectives about funding and policies for autism funding, and their experiences must be considered in creating policies and programs.

Keywords: autism; social justice; policy creation; qualitative methods; disability

Centering Autistic Persons' Perspectives in Autism Social Policy: A Qualitative Study

In autism program development news and research, there is often a bias towards including policymakers, service providers, and parent opinions (Shepherd & Waddell, 2015). The opinions of autistic adults have not been widely sought or represented comprehensively in policy-oriented research. By investigating autistic adults' expectations and perspectives of Ontario's autism programs and policies, this study sought to bring the perspectives of autistic adults, often excluded from conversations about autism policy, to inform autism policy in Ontario. Informed by Critical Autism Studies using a structural framework, which identifies influential systems and policies on individual well-being, and understanding autistic persons as experts in autism, this paper draws from a qualitative study that highlights the need to center autistic persons' lived experiences and voices in creating autism policy. This approach ties principles of Participatory Action Research (PAR), influenced by Baum et al., (2006), to demonstrate the utility of understanding self and subjectivity in a social policy context.

In-depth semi-structured interviews with four autistic adults (one woman, three men) who held opinions about autism policy in Canada bring into public awareness the need for societal education programs to

understand autistic identity, as well as identify areas where government support is inadequate and areas of government support that hold potential for equity and inclusion of autistic persons in the Canadian context. Furthermore, the autistic adults interviewed also identified future avenues for including autistic persons and their communities of care in creating policies and programs that can impact autistic persons positively. The findings support calls for inclusion of autistic persons in policy creation about autism and disability, identifying that without these inclusive measures, there will continue to be systemic inadequacies within social policy surrounding autism and disability, especially in medical and education systems. Understanding the importance of autistic perspectives holds potential to provide insights for social workers in continuing to work towards equity, access, inclusion, and diversity.

Autism as a Concept

Central to autism policy creation is an understanding of autism as a concept. However, autism is an often-contested term, defined differently across time, within biomedical discourses, and by autistic self-advocates. In situating this research socio-politically, understanding these different conceptions of autism is necessary to explore the broader range of perspectives involved in autism program and policy creation.

The term “autism” was coined by psychiatrist Eugen Bleuler in 1911 (Milton, 2014b). The subsequent diagnosis of autism is often credited to two central figures, “two pioneers of autism”: American psychiatrist Leo Kanner and Austrian pediatrician Hans Asperger (Lyons & Fitzgerald, 2007, p. 2002, as cited in Maich & Hall, 2016, p. 4). These early scholars described autism as a pathology.

Autism was eventually included as a diagnosis in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* [DSM] (American Psychiatric Association, 1980). Historically, autism had been recognized as “childhood schizophrenia,” defined in the DSM-II (Milton, 2014b, p. 1). Autism was eventually separated as a developmental disorder within the DSM and is currently defined in the DSM-5 (2013) as a compilation of “deficits” in social communication and social interaction, and restricted and repetitive patterns of behaviour/interests/activities (American Psychiatric Association, 2013, pp. 50-51, as cited in Maich & Hall, 2016, p. 35).

Service provision in Ontario for autistic people is contingent upon a diagnosis of autism based on the DSM criteria stated above. However, other definitions of autism have become more popular, which recognize it as socially constructed in nature and as a neurological condition (Haney, 2018). Autistic advocates have reframed autism by questioning non-autistic understandings of autism (Gillespie-Lynch et al., 2017; Milton, 2014a; Sinclair, 2013; Verhoeff, 2012). They proposed autistic identity as a social identity category, and autism as an inherently valuable way of living in the world (McGuire, 2012).

Situating the Research (Table 1)

Traditionally in Ontario, autism program development has centered the perspectives of policymakers, service providers, and parents (Shepherd & Waddell, 2015). Autism policy in Ontario developed as a result of parent and caregiver advocacy, which pushed for greater financial and social support in behavioural services (Perry, 2002). Researchers, policymakers, and parents have historically been disappointed by autism-focused litigation outcomes and reactive policymaking (Shepherd & Waddell, 2015). Advocacy groups have demanded a National Autism Strategy in Canada (Canadian Autism Spectrum Disorder Alliance, 2019), and researchers have noted that there are economic cost-savings associated with implementing policy that guarantees the provision of behavioural services to all autistic children (Motiwalla et al., 2006).

In 2017, the Ontario Autism Program (OAP) was created to provide “evidence-based services delivered according to a relevant assessment of a child or youth’s needs, strengths and interests, as well as the

family's concerns and priorities" (Ministry of Children and Youth Services (MCYS), 2018). While Ontario had two previous programs, the 1999 Early Intervention Program for children aged 2 to 5 years old (Perry, 2002) and the Autism Intervention Program in 2006, the OAP was intended to be a comprehensive and family-centered program, which focused on allocating funding to "evidence-based therapy" Applied Behaviour Analysis (ABA) (MCYS, 2018).

ABA, while supported by evidence for behavioural and educational outcomes in children with autism, has been rejected by many autistic writers, advocates, and self-advocates, criticized for painting autistic persons as "deviant" (Gibson & Douglas, 2018; Yergeau, 2017). Not all people agree that ABA is a preferred method or that ABA provides preferred outcomes. However, under the OAP, families could access intensive ABA for children six and under by means of a direct service option, which placed families on a waitlist to work with a regional provider to develop a plan of service for their child. Alternatively, they could access intensive ABA through a direct funding option for services that were found within the OAP behaviour plan, giving caregivers the responsibility for choosing a provider for appropriate and approved services (MCYS, 2018). Most services provided under the OAP required providers to have training, supervision, and/or certification in ABA (MCYS, 2018). After a child aged out of the intensive ABA services, they would receive smaller amounts of less intense services, if recommended based on their individualized behaviour plan (MYCS, 2018).

In 2019, a new program called the Childhood Budgets program was proposed (Slaughter, 2018). This program offered an age-based cash benefit contingent on a diagnosis of autism. The Childhood Budgets program provides parents of autistic children under age six with an annual allotment of \$20,000, and caregivers of autistic children between six and 18 years old with an annual budget of \$5,000 (Ministry of Children, Community, and Social Services (MCCSS), n.d.). Under this new funding option, the provincial government was removed from the delivery of direct services of ABA and coordinating services were offloaded onto individuals and families. When announced, the new program was rejected publicly (Crawford, 2019; Laucius, 2019a; Laucius, 2019b; Payne, 2019a; Payne, 2019b; Adam, 2019). There was an explosion of advocacy activity by parents and caregivers who argued that the allocated funding was insufficient to cover ABA therapy, which was covered in many news stories (Crawford, 2019; Laucius, 2019a).

In response to the public advocacy across the province, including protests and complaints by organizations such as Ontario Autism Coalition (Kirby-McIntosh, n.d.), the Ontario government replaced the Minister of Children, Community, and Social Services (Alphonso & Stone, 2019; Laucius, 2019c) and called for community consultations (MCCSS, 2019a). This call resulted in bringing together a committee to develop the *Ontario Autism Advisory Panel Report* (MCCSS, 2019b), which aimed to create a new needs-based program. However, on December 17, 2019, this new program was delayed by a year. Direct services allotted under the old OAP were extended for a year, and "interim one-time funding" was extended to new program enrollments under the Childhood Budgets for 2020-2021 (Stone, 2020). Since the COVID-19 pandemic, the Ontario government extended the time for submitting expenses for the one-time funding and spending to the Childhood Budget funding for six months. Those who were Ontario Autism Program recipients continue to have their services extended as of February 2020 (MCCSS, 2020).

The autism policy and program development in Ontario has traditionally left out autistic persons' opinions of priorities and needs. Opinions of autistic people have not been widely sought or represented comprehensively in policy-oriented research. This study aims to make a small but important contribution in this regard by bringing the perspectives of autistic adults, often excluded from conversations about autism policy, to inform autism policy in Ontario.

Table 1. The Politicization of Autism in Ontario

Early Intervention Program (1999)	<ul style="list-style-type: none"> • Intensive Behaviour Intervention (IBI). • Ages 2 to 5 “to children with autism or a disorder which would be considered the more severe end of the continuum known as Autism Spectrum Disorder” (Perry, 2002, p. 122).
Autism Intervention Program (2006)	<ul style="list-style-type: none"> • IBI from a regional agency. • Direct service or direct funding option, accessed through diagnosis by doctor or psychologist. • Nobody "cut" from services based on age (MCCSS, 2007). • Features transition support to schools (Turan, 2014).
Ontario Autism Program (2017/18)	<ul style="list-style-type: none"> • Direct-service or direct funding option, working with a regional provider. • Requirements for IBI and ABA providers in training, supervision, and/or certification in ABA. All services must fall under the OAP behaviour plan (MCYS, 2018).
Childhood Budgets (2019)	<ul style="list-style-type: none"> • Removal of direct-service option and behaviour plan for a cash-based benefit contingent on diagnosis. • Age-based funding (under 6, \$20,000/year and between six and 18, \$5,000/year. Limit of \$140,000 total funding). • Not only ABA/IBI services included in eligible services (MCCSS, n.d.).

Including the Autistic Expert in Autism Policy Creation

While program and policy creation has traditionally centered perspectives of non-autistic persons, autistic persons have long been promoting autistic rights and identifying the need for consultation and inclusion. Structural criticisms surrounding disability, which sought to change concepts that are typically seen as personal into political issues (Carniol, 1992; Crenshaw, 1989; Titchkosky & Michalko, 2009), brought into consideration inclusionary understandings of diversity and disability. With this, came the emerging understanding that autistic persons are experts of their own lives (Gillespie-Lynch et al., 2017; Milton, 2014a, Woods et al., 2018).

Critical Autism Studies, an emerging scholarly field, stems from Critical Disability Studies. Both fields developed in reaction to biomedical models of disability, identifying that disability and impairment are socially constructed, and that it is the environments, social oppression, and discrimination that in-fact disable (Hall, 2019; Woods et al., 2018). Understanding autism as a concept which is socially constructed, and the autistic experience as framed by oppression, justifies the need for autistic inclusion/exclusion in social policy development to be critically analyzed, and for a participatory methodology to be used in creating dialogues about social policy creation.

Paulo Freire was a foundational influence in promoting participatory methodologies, demonstrating that research could be used to enable critical consciousness and instigate social change (Coghlan & Brydon-Miller, 2014). Social change that results from such research cannot be researcher focused but should be community-driven, therefore suggesting that autistic community members must be centered in providing avenues for autism policy improvement and political developments for inclusive policy-creation. This research employed aspects of PAR as defined by Baum et al., (2006) through critical inclusion of autistic perspectives in interviews, peer-debriefings with autistic community members, and involvement from partners.

Study Methods

This study draws from in-depth interviews with four autistic adults in 2019 on their perspectives and opinions of autism policy in Ontario. Respondents were recruited with the help of community collaborators who were partners in the research process, involved in supervision, recruitment, and consultation throughout the research process, and critiqued ethics and research design to ensure the research was conducted in good faith. Partners included a manager at the researcher's university's centre for students with disabilities, a faculty member with knowledge of potential participants, an experienced counsellor of autistic adults, and a well-connected leader in autistic communities who is also the co-founder of two autistic-led advocacy organizations. Another partner, who was not directly involved in the recruitment process but was involved in peer-debriefing and methods critiquing, was an autistic co-author of a book on women's perspectives of autism. The researcher secured partnerships through membership with a critical disability association, a research assistantship on autism and representation, and volunteer work with a local adult autism initiative.

Table 2. Interview Participant Characteristics

Participant	Interview Details Location (in person, online, or phone) Length (min)	Characteristics Occupation (student, employed, unemployed) Gender (woman, man) Race (white, visible minority)	Direct experience with ABA
Rudy	In-person 72 min Sept 22, 2019	Employed Woman White	Yes
Tom	In-person 58 min Sept 25, 2019	Unemployed Man White	Unknown
James	In-person 52 min Oct 29, 2019	Full-time student Man White	No
Philip	In-person 25 min Nov 1, 2019	Full-time student Man White	No

All participants self-identified as autistic/being a person with autism, were over the age of 18, lived in Ontario, and had experiences with ABA or autism funding (Table 2). As documented with other populations in the literature (Babbie & Benaquisto, 2014), finding participants who met the inclusion criteria—autistic adults who can and are interested in participating in research and who have opinions about autism funding in Ontario—proved challenging. Despite the small number of participants, the interview format allowed for thick description: a deeper description of opinions, events, and impacts of each participant individually, rather than a surface description of common traits of an average population (Denzin, 2001). All participants were compensated for their time, travel, and accommodation. Digital interview formats were also presented as an option.

All interviews were recorded and transcribed verbatim. The researcher took detailed notes engaging in critical self-reflection, allowing for a deeper understanding of participants' perspectives and reflection on the researcher's role in influencing interview data. This reflexive process was intended to minimize power imbalances in subsequent interviews and increase trustworthiness of findings during analysis (Daley, 2010). While the sample size was small, the rich participant narratives emphasize the need for inclusive creation that recognizes autistic persons as experts in their lives, experience, and relevant, appropriate,

and urgent social policy needs.¹ It would have been ideal to have a larger sample size of participants with diverse social locations; however, this was not possible due to researcher capacity. All names in the results quoted below are pseudonyms.

Results

Autism as a Concept and Identity to be Widely Understood

Participants stressed the need to identify and define autism, in addition to how autism influenced their lives and identities during interviews. They shared the importance of their diagnosis on their identity development. Rudy described, “for me... when I describe myself and when it comes to diagnosis, I say specifically diagnosed with Asperger’s Syndrome because I think that that is more accurate about the nature of where I would get such a label.” James recalled, “from my diagnosis I know that I am a lot more high-functioning than most people on the autism spectrum. I was originally diagnosed with Asperger’s, but that was... back when the DSM-IV was still in control of those things.” He also recalled his difficulty in obtaining diagnosis, saying “I was misdiagnosed many times.” Tom recalled that he was diagnosed at an early age but did not know about the diagnosis until he was older. He said,

They got me patted down as autistic when I was like two... My mom took me to some people... and then they’re like ‘yeah, your kid is borderline autistic.’ But I didn’t find out about that until I was 11 or so.

There are significant barriers to accessing autism diagnosis in Ontario, especially past the age of 18, and diagnosis is viewed as a milestone in autism acceptance and accessing subsequent support (Crane et al., 2019). Participants raised the process and barriers of diagnosis as a social policy issue and stressed the importance of increasing access for autism diagnosis.

In addition to diagnosis, participants identified the need for autism policy development to address the rising prevalence rates. It is estimated that 1 in 66 children and youth in Canada have a diagnosis of autism (Ofner, et al., 2018). In the discussion regarding autism services and policy, participants argued that autism is highly prevalent and gave estimates on how many people are autistic. Participants emphasized the importance of recognizing and acknowledging the prevalence rates as a motivation and point of departure for advocacy with and by autistic persons, which they argued must be invoked in policy development that increases access to important services and supports. Rudy used prevalence rates to support arguments concerning autism policy, saying, “having at least one family member diagnosed with autism... is becoming more a norm because of increases in diagnosis rates...It has become a sizable minority population that their voice has to be considered.”

Prevalence rates also allowed participants to advocate for increased awareness of autism, to, as Tom said, “demystify” and “de-monstrify” autism, and a recognition that “many of us are kinda [sic] normal.” This conceptualization of autism as a normative human difference echoes in Critical Autism Studies research that aims to “re-story” autism as “relational, generative, and desirable” in humanity (Douglas et al., 2019, p. 14). As James said, “just like anybody else, autistic people are individuals.”

Stigma is a significant factor in selfhood and identity creation of autistic persons. McGuire (2012) argues that the stigmatization of autistic individuals is rooted in historical perspectives of autism, the language that surrounds autism, and public images of autism. Philip identified that stigma prevents people from disclosing their autism, saying “I find for many people they want to keep their autism a secret.” When speaking about the employment context, James also noted that he refrained from disclosing his autism to

¹ This research was cleared by Carleton University’s Research Ethics Board (Clearance no. 111389, Sept 2019).

his employers, “every time I have been employed by someone, I have not disclosed it.” Finally, Tom called for a societal change in perceptions of autism, saying,

Too long we have associated autistic people with like clowns or like people to laugh at... they need to unveil the misconceptions and show that autistic people have potential to be people like us, or people like you in this case.

Overall, participants reiterated the need for social policy to prioritize diagnosis of autism in conjunction with increased and appropriate public autism education for non-autistic persons to naturalise autism. This, in turn, leads to consulting and involving autistic persons in policy-creation and service development.

Socially Funded Services and Supports Not Relevant for all Autistic Persons

Ontario’s social policies concerning autism focus on providing behavioural supports for autistic children. This reflects the priorities of policymakers, service providers, and parents (Shepherd & Waddell, 2015) and has been widely critiqued by autistic advocates (Gibson & Douglas, 2018; Yergeau, 2017). While Applied Behaviour Analysis (ABA) therapy is the focus of autism policy in Ontario, only one participant recalled direct experience in ABA. Other participants may have had experiences in ABA but did not specifically name or have knowledge of ABA. Philip, who had no knowledge of what ABA is, states “what is applied...?” And, while James had heard of ABA, he had no experience with it directly, saying “I am not entirely up to date on the ABA... I know I have heard of it, and I know that I may have read a few things here or there, um, but I couldn’t think of it off the top of my head.”

Rudy was the only participant who recounted direct experience in ABA-based programming as both a learner in ABA-based programs and through current employment within an ABA/IBI service. Reflecting on her and her sister’s experience in ABA-based programming, Rudy took a “pragmatic” approach when describing ABA therapy:

I don’t attribute it as the end-all-be-all for autism therapy... I think some of the biggest benefits that I got from ABA and IBI was about taking turns and also about being respectful about people’s personal space, and... knowing that doing certain actions might result in a little bit of fun time after.

Rudy also accessed alternative therapies, and describes that ABA is one of a plethora of therapies that she attributed to her own growth and well-being:

So, ABA and IBI... sensory-integration therapy, Montessori-based therapy, I mean all the way down to wearing weighted vests to have us sleep better. I mean, what kind of therapy did we not try... Oh, and also speech therapy... They all benefitted us to varying degrees...

Another behavioural therapy that was reviewed by a participant was Cognitive Behaviour Therapy (CBT). James, who received these services as a teenager, said “I owe a lot... to CBT and highly recommend it.” With relation to additional supports, Philip expressed an appreciation for a weighted blanket as a teenager to alleviate his anxiety. While there was discussion of useful supports and services, other supports were identified as non-preferred. Philip identified that he did not enjoy counselling, as it was often deficit-focused and concentrated on behaviour reduction strategies.

Participants also identified areas where services and supports needed to be extended. In identifying areas for growth, participants spoke about a gap in service provision for adults in Ontario. Rudy argued that, “what is becoming more apparent in the past few years is the almost complete lack of services for adults who are diagnosed with autism.” Further, Philip expressed that there is not only a lack of services but also a lack of funding to access appropriate services for autistic adults, saying “I didn’t get much time to get

support, cus [sic] I was diagnosed at 16... when you turn 18 the funding stops. It cuts. So, paying for that with your own funds is like paying for your autism.” Tom identified that there is a need for job assistance programs for autistic people and also called for additional social supports “catered to autistic people” in the form of “organized hangouts.”

Participants acknowledged that the needs of autistic adults and children could be better met through the provision of employment assistance services, organized social activities, and promotion of self-advocacy. Based on participant responses, it is clear that underfunded services of non-behavioural therapies, CBT, and adult-based services are all valued by autistic adults and would benefit social policy development. Including autistic persons' past experiences and understandings of needs in terms of policy and service provision is a valuable contribution to promote equitable, engaged services for autistic and non-autistic children and adults.

Complicating Factors in Autism Policy Creation: Medication and Education

A common theme of the interviews was provincial public health policies and education policies and their impact on autistic persons in Canada. The *Canada Health Act* (1984) provides reasonable access to health care for all Canadians and is funded through provincial and federal tax dollars (Government of Canada, 2002). Access to provincial medical services allows participants to get necessary prescriptions. While prescription drugs are not covered under the *Canada Health Act* (1984), some people in Ontario get prescription medication covered through employment/private insurance plans. While medication is regarded as complementary to social services in supporting autism therapy (Ip et al., 2019), there are few medications which are specific for autism itself (Accordino et al., 2016; Williamson & Martin, 2012).

Philip referred to his use of medication as something he does not necessarily recognize the effects of, saying, “if I switch pills, I won't see a difference, but my parents can.” Both Tom and James identified that they were prescribed medications, usually used for ADHD (stimulants), and that these medications had negative impacts on them as children. Tom referred to his experiences with his mother administering his ADHD medication to him as a child as “drinking pills... in Jell-O form.” He advocated that these medications are not a quick fix for autism, saying,

You can't really solve a problem by giving them medicine... When I was a kid, I was given Ritalin... I was well aware. And one day my mom realised that the Ritalin was making me more zombie like, so then we switched to Concerta, until I just stopped.

The lack of adequate funding, services, and supports for autism in Ontario may increase a person's drive to try medications in order to cope with some of the behaviours associated with autism rather than understanding the function of and targeting those specific behaviours. James recalled,

I was a really little kid, and so my parents would talk to him [the doctor] and do most of the talking for me... he tried me on every single ADHD med under the sun... I was in the worst place that I have probably ever been in my entire life.

At the same time, medication was expressed as a tool of empowerment and useful for a person to live their best life. James identified that ADHD medication was appropriate as a young adult in negating the weight gain side-effect of taking Abilify (aripiprazole), an atypical antipsychotic drug. Tom identified that he would have liked the medication that he is currently on to be offered at an earlier age, rather than a “calming room” (seclusion room), which was used in his school environment as a means to control his emotional responses of anger. He stated,

I am still taking medication today, but it is probably for more appropriate measures. And I think that what I should have been doing back then, if I decided to go back, is recommend [sic]

Ciprex to prevent overstress, and if I get too stressed, don't put me in the calming room, just have me take Lorazepam.

Medication was seen as a support for autism by these participants. This may be due to the relative ease of accessing and attaining medication in Canada, whereas attaining social services often requires waitlists, time, and financial commitments.

Participants also understood that supports and services were offered through educational institutions that they had interacted with. The Canada Social Transfer gives provinces the responsibility of creating education policy and subsequent policies and services (Government of Canada, 2011). In the educational environment, autistic children may face barriers in accessing appropriate supports and services. Tom indicated that there were barriers to inclusion when speaking about segregation in the school environment. James indicated that his school was inadequately prepared to identify autism. Barriers led participants to mistrust their schools. Philip, reflecting on the inability to provide supportive education, said, "it kind of felt like they wanted the papers (proof of diagnosis) to get money for the school, but they didn't really care about helping me."

Tom, in describing his experiences in the "calming room," expressed a call for the use of seclusion rooms to end. Tom indicated that seclusion rooms may have had long-lasting consequences and suggested that PRN ('as needed') medication could be an alternative to use of seclusion rooms. While participants appreciated supports and services offered through the education system, such as accommodations, they also indicated that integration was important within classroom environments. James stated that autistic people need to "learn how to work in the real world just as everybody else." Like other students, autistic students are, as Philip acknowledged, "kinda normal."

In balancing adequate and non-stigmatizing education for autistic children, Rudy expressed that education about autism should be offered to all children. This support would implement more conversations around disability acceptance. As a result, long term "societal empathy" would increase, and discrimination based on ability would diminish. Therefore, a more global identification of autism policy and funding would incorporate systemic change, not only providing educational opportunities for autistic students, but also their peers and those who interact with autistic students. Consulting autistic persons about their experiences with medication and in education, rather than relying on "experts" who provide outsider perspectives, holds potential for improving understandings of the lived experiences of autism, exploring new avenues to promote best outcomes for children and adults.

Avenues for Improvement in Social Policy Surrounding Autism

Autistic children often receive supports and services outside of the medical and education system. These supports and services, however, may be limited due to financial constraints. Participants reflected on the inadequacies of provincial policies in providing adequate funding as children and in adulthood. At the same time, participants were apologetic of the additional needs of autistic persons, expressing that they could see autism funding as economically difficult to sustain through social policy.

Rudy said, "Given currently [sic] Canada's economy... I think that families being put in a position to be able to pay for services without doing some serious considerations such as taking out a loan or mortgaging their home." Philip supported this, proposing that stigmatization of autism increases if families are required to fund their own services and supports. He said, "I think a family shouldn't have to pay for having an autistic child because that can sometimes make it look like the autistic child's a burden." However, James said that people who could afford to pay for services, should, as market considerations may incentivise service provider quality and meaningful service use by clients. He said, "it's not on the government to pay for things that can already [be] paid for by that person... I also think that gives me more of an incentive to use those services."

The complete lack of funding for autistic adults was highlighted by Philip and Tom. Philip stated that he would prefer to see funding “saved up and to be used on that person for beneficial reasons... such as post-secondary education or just continual services in their life,” rather than only given during childhood. Tom referred to Ontario’s Disability Support Program (ODSP) and identified that the funding he received through this program as an adult is inadequate in a society with increasing costs.

Participants agreed that policies about autism funding should be inclusive of autistic voices and their parents. Tom and Philip identified that autistic people were not being consulted when policies were being created. Tom stated, “they need opinions from autistic people. Even if they don’t really have any kind of ideas of what they want. Ask them what they need, and they’ll say what they need.” Rudy added, “I do think there needs to be more inclusion with persons diagnosed with autism on serious issues.” Philip also identified that there is more of a focus on people who ‘deal’ with autistic people when creating policies, “I think that one thing that they’re doing is they’re taking more the opinions of people who deal with autistic people, so they’re taking the counsellors, of the parents, instead of the actual autistic people.”

While there are not as many barriers for parents and caregivers, participants did not think that autistic people should be the only people defining autism policies. Tom believed, “at least have autistic children, to understand the struggles... because having an autistic children [sic] means you kind of understand how it is going on, how the children acts, how the children reacts [sic].” Philip also stated, “I think they should be like half and half... you need another perspective of someone who’s not autistic... for balance if that makes sense... like both points of view.”

Participants all agreed that autistic people should be considered and consulted when creating policies surrounding autism. Structural change must be inclusive of a diversity of voices, and, in particular, must center autistic people as experts when developing social policy that impact autistic people and their communities of care.

Discussion and Conclusions

All participants would agree that they do not feel adequately supported by autism policy in Ontario, Canada, and do not feel included in autism policy creation. This reflects the current state of autism program development news and research, which is biased in favour of non-autistic policymakers, service providers, and parent opinions (Shepherd & Waddell, 2015). The province has had a number of policy developments to support autistic children and their families since 1999; however, including autistic persons’ perspectives in creating these policies had not been adequately explored. Confident and appropriate diagnosis of autism is an important first step, which is often difficult to access but vital to identity formation for participants, and a prerequisite for receiving funding at any age in Canada and by many insurers around the world. Social policy which centers and prioritizes funding appropriate and effective diagnosis will have significant positive outcomes for autistic individuals’ well-being, as well as for identity and community formation among persons diagnosed with autism.

While many social policies focus on providing ABA as a support for autism, ABA and other behavioural approaches were not the only valued support by participants. Listening to autistic persons as experts on their own experiences can assist policymakers in determining supports and additional funding in relevant areas, such as medication in older ages, employment, and social development groups. Governments should also consider phasing out or defunding problematic policies, such as seclusion and exclusionary policies in education. Finally, it must be emphasized that the autistic persons are experts, and all policies should be made with and by them. Their opinions must be central to developing autism policies and allocating funding, which in turn shapes the services and support they can receive during their lifetime.

Integrating the lived experiences of autistic persons to create opportunities for inclusiveness at the macro level has the potential to influence and inform future social policies. Social workers, who work towards social justice, can work with autistic clients and communities in working towards equity, inclusion, and accessibility. Historically, autism policy and research about policy development has centered the perspectives of non-autistic researchers, policymakers, and parents (Perry, 2002; Shepherd & Waddell, 2015). This study, although limited in scope, demonstrates that autistic persons have meaningful contributions to make in advising policy development and redevelopment. There is room for improvement in creating inclusive policies that offer a broader range of supports for a growing and vulnerable population. While the study is regionally specific, the multitude of voices demonstrate the urgent need for future research surrounding autism policy that engages meaningfully with autistic persons as experts in this field, as well as the importance of iterative policy development which is proactively inclusive and accommodates community consultations, feedback, and ongoing cooperation with contextual and societal changes. Social policy that is seen as living has potential to prevent pushback and social upheaval, increase transparency, and decrease power differentials between those who implement policy and those impacted by said policies.

References

- Accordino, R. E., Kidd, C., Politte, L. C., Henry, C. A., & McDougale, C. J. (2016). Psychopharmacological interventions in autism spectrum disorder. *Expert Opinion on Pharmacotherapy*, 17(7), 937–952. <https://doi.org/10.1517/14656566.2016.1154536>
- Adam, M. (Feb 26, 2019). Adam: Doug Ford and Lisa MacLeod need to start over on Ontario autism plan. *Ottawa Citizen*. <https://ottawacitizen.com/opinion/columnists/adam-doug-ford-and-lisa-macleod-need-to-start-over-on-ontario-autism-plan>
- Alphonso, C., & Stone, L. (2019, July 1). Autism advocates calling for Ontario to adopt full program reset laid out in PC MPP's review. *The Globe and Mail*. https://www.theglobeandmail.com/canada/article-autism-advocates-calling-for-ontario-to-adopt-full-program-reset-laid/?utm_source=Shared+Article+Sent+to+User&utm_medium=E-mail:+Newsletters+:+E-Blasts+:+etc.&utm_campaign=Shared+Web+Article+Links
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.).
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Babbie, E. & Benaquisto, L. (2014). *Fundamentals of Social Research* (3rd Canadian ed.). Nelson Education Limited.
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology & Community Health*, 60(10), 854-857. <https://doi.org/10.1136/jech.2004.028662>
- Canadian Autism Spectrum Disorder Alliance (CASDA). (2019). *Blueprint for a National Autism Spectrum Disorder Strategy*. <https://www.casda.ca/wp-content/uploads/2019/03/Blueprint-for-a-National-ASD-Strategy-1.pdf>
- Government of Canada. (2002). *Federal transfers to provinces and territories*. <https://www.canada.ca/en/department-finance/programs/federal-transfers.html>
- Government of Canada. (2011). *Canada Social Transfer*. <https://www.canada.ca/en/department-finance/programs/federal-transfers/canada-social-transfer.html>
- Carniol, B. (1992). Structural social work: Maurice Moreau's challenge to social work practice. *Journal of Progressive Human Services* 3(1). 1-20. https://doi.org/10.1300/J059v03n01_01
- Crawford, B. (Feb 15, 2019). Parents keep pressure on Lisa MacLeod over autism changes. *Ottawa Citizen*. <https://ottawacitizen.com/news/localnews/parents-keep-pressure-on-lisa-macleod-over-autism-changes>
- Coghlan, D. & Brydon-Miller, M. (2014). Freire, Paulo. The SAGE Encyclopedia of Action Research. <https://doi.org/10.4135/9781446294406.n150>

- Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). "Something needs to change": Mental health experiences of young autistic adults in England. *Autism: The International Journal of Research and Practice*, 23(2), 477–493. <https://doi.org/10.1177/1362361318757048>
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*, 1(8), 139-167. <https://chicagounbound.uchicago.edu/cgi/viewcontent.cgi?article=1052&context=uclf>
- Daley, A. (2010). Reflections on reflexivity and critical reflection as critical research practices. *Affilia*, 25, 68-82. <https://doi.org/10.1177/0886109909354981>
- Denzin, N. K. (2001). *Interpretive Interactionism* (2nd ed.). Applied Social Research Methods Series Vol. 16. Sage Publications, Inc.
- Douglas, P., Rice, C., Runswick-Cole, K., Easton, A., Gibson, M. F., Gruson-Wood, J., Klar, E., & Shields, R. (2019). Re-storying autism: A body becoming disability studies in education approach. *International Journal of Inclusive Education*, 0(0), 1–18. <https://doi.org/10.1080/13603116.2018.1563835>
- Gibson, M. F., & Douglas, P. (2018). Disturbing behaviours: Ole Ivar Lovaas and the queer history of autism science. *Catalyst: Feminism, Theory, Technoscience*, 4(2), 1–28. <https://doi.org/10.28968/cftt.v4i2.29579>
- Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*, 8. <https://doi.org/10.3389/fpsyg.2017.00438>
- Hall, M. C. (2019). Critical Disability Theory. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2019). Metaphysics Research Lab, Stanford University. <https://plato.stanford.edu/archives/win2019/entries/disability-critical/>
- Haney, J. L. (2018). Reconceptualizing autism: An alternative paradigm for social work practice. *Journal of Progressive Human Services*, 29(1), 61–80. <https://doi.org/10.1080/10428232.2017.1394689>
- Ip, A., Zwaigenbaum, L., & Brian, J. A. (2019). *Post-diagnostic management and follow-up care for autism spectrum disorder*. Canadian Paediatric Society. <https://www.cps.ca/en/documents/position/asd-post-diagnostic-management>
- Kirby-McIntosh, L. (n.d.). History. *Ontario Autism Coalition*. <https://ontarioautismcoalition.com/history/>
- Laucius, J. (2019a, Feb 8). Provincial reforms to autism supports. *Ottawa Citizen*. <https://ottawacitizen.com/news/local-news/parents-rally-to-protest-provincial-reforms-to-autism-supports>
- Laucius, J. (2019b, Feb 15). Primer: Applied Behaviour Analysis, the therapy at the heart of Ontario's autism controversy. *Ottawa Citizen*. <https://ottawacitizen.com/news/local-news/primer-applied-behaviour-analysis-the-therapy-at-the-heart-of-ontarios-autism-controversy>
- Laucius, J. (2019c, February 20). Ontario's new autism program could save the province up to \$100 million, says economist. *Ottawa Citizen*. <https://ottawacitizen.com/news/local-news/ontarios-new-autism-program-could-save-the-province-up-to-100-million-says-economist>
- Maich, K. & Hall, C. (2016). *Autism spectrum disorder in the Ontario context: An introduction*. Canadian Scholars' Press Inc.
- McGuire, A. (2012). Representing autism: A sociological examination of autism advocacy. *Atlantis: Critical Studies in Gender, Culture & Social Justice*, 35(2), 62–71. <https://journals.msvu.ca/index.php/atlantis/article/view/918>
- Milton, D. (2014a). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*. <https://doi.org/10.1177/1362361314525281>
- Milton, D. (2014b). *So what exactly is autism?* Autism Education Trust. <https://kar.kent.ac.uk/62698/>
- Ministry of Children and Youth Services [MCYS]. (2018). *Ontario Autism Program (2018) guidelines*. Ontario. <https://www.ontario.ca/document/ontario-autism-program-guidelines>
- Ministry of Children, Community, and Social Services [MCCSS]. (n.d.). *Ontario Autism Program*. Ontario. <https://www.ontario.ca/page/ontario-autism-program>

- Ministry of Children, Community and Social Services [MCCSS]. (2007). *McGuinty government investing in more services for children and youth with autism*.
<https://news.ontario.ca/archive/en/2007/08/17/McGuinty-Government-Investing-In-More-Services-For-Children-And-Youth-With-Autis.html>
- Ministry of Children, Community, and Social Services [MCCSS]. (2019a). *Ontario autism consultations now open*. Ontario Newsroom. <https://news.ontario.ca/en/release/52047/ontario-autism-consultations-now-open>
- Ministry of Children, Community, and Social Services [MCCSS]. (2019b). *The Ontario autism program advisory panel report*.
<http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/autism/AutismAdvisoryPanelReport2019.pdf>
- Ministry of Children, Community, and Social Services [MCCSS]. (2020). *Ontario Autism Program news and program updates*. Ontario. <https://www.ontario.ca/page/ontario-autism-program-news-and-program-updates#section-3>
- Motiwala, S., Gupta, S., Lilly, M., Ungar, W., & Coyte, P. (2006). The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy = Politiques de Santé*, 1, 135–151. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585334/pdf/policy-01-135.pdf>
- Ofner, M., Coles, A., Decou, M. L., Do, M. T., Bienek, A., Snider, J. & Ugnat, A. M. (2018). *Autism Spectrum Disorder among children and youth in Canada 2018: A report of the National Autism Spectrum Disorder Surveillance System*. Public Health Agency of Canada.
<https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018/autism-spectrum-disorder-children-youth-canada-2018.pdf>
- Payne, E. (2019a, Feb 6). Clear waiting lists, give money to parents. *Ottawa Citizen*.
- Payne, E. (2019b, Feb 25). Documents suggest Ontario autism wait list frozen last fall, parents not told. *Ottawa Citizen*. <https://ottawacitizen.com/news/local-news/documents-suggest-ontario-autism-wait-list-frozen-last-fall-parents-not-told>
- Perry, A. (2002). Intensive early intervention program for children with autism: Background and design of the Ontario preschool autism initiative. *Ontario Association on Developmental Disabilities*, 8.
<https://oadd.org/wp-content/uploads/2016/12/art11Perry.pdf>
- Shepherd, C. A., & Waddell, C. (2015). A qualitative study of autism policy in Canada: Seeking consensus on children's services. *Journal of Autism and Developmental Disorders*, 45(11), 3550–3564. <https://doi.org/10.1007/s10803-015-2502-x>
- Sinclair, J. (2013). Why I dislike “person first” language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2), Article 2. <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1>
- Slaughter, G. (2018, June 7). Doug Ford's Progressive Conservatives win majority in Ontario. *CTVNews*.
<https://www.ctvnews.ca/canada/doug-ford-s-progressive-conservatives-win-majority-in-ontario-1.3963986>
- Stone, L. (2020, January 24). Ontario extends autism funding until new program in place. *The Globe and Mail*. <https://www.theglobeandmail.com/canada/article-ontario-extends-autism-funding-until-new-program-in-place/>
- Titchkosky, T. & Michalko, R. (2009). *Rethinking Normalcy: A Disability Studies Reader*. Canadian Scholars' Press Inc.
- Turan, M. (2014). *Family Perspectives on the Ontario Autism Intervention Program*. [Unpublished Doctoral Dissertation.] University of Windsor.
<https://scholar.uwindsor.ca/cgi/viewcontent.cgi?referer=https://scholar.google.com/&httpsredir=1&article=6189&context=etd>
- Verhoeff, B. (2012). What is this thing called autism? A critical analysis of the tenacious search for autism's essence. *BioSocieties*, 7(4), 410–432. <https://doi.org/10.1057/biosoc.2012.23>

- Williamson, E. D., & Martin, A. (2012). Psychotropic medications in autism: Practical considerations for parents. *Journal of Autism and Developmental Disorders*, 42(6), 1249–1255.
<https://doi.org/10.1007/s10803-010-1144-2>
- Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining Critical Autism Studies: A more inclusive interpretation. *Disability & Society*.
<http://www.tandfonline.com/doi/abs/10.1080/09687599.2018.1454380>
- Yergeau, M. (2017). *Authoring Autism*. Duke University Press. <https://www.dukeupress.edu/authoring-autism>

Acknowledgements: This research was supported in part by funding from the Social Sciences and Humanities Research Council, Carleton University's School of Social Work, Faculty of Graduate and Postdoctoral affairs, and Faculty of Public Affairs. This research was originally conducted in partial fulfillment of the requirements for the degree of Master of Social Work under supervision of Dr. Roy Hanes and Dr. Miranda Brady. I wish to thank Dr. Amrita Hari and Dr. Karim Abuawad for supporting the development of this paper. I sincerely thank the anonymous peer reviewers whose comments and suggestions improved this manuscript.

Margaret G. Janse van Rensburg, MSW is a doctoral Student at Carleton University. Her current research interests include the social model of disability, autistic self-determination, sexual violence prevention, and eating disorders.

Understanding the Impact of Neoliberalism and Racism on the Food Insecure within Food Pantries: A Book Review

Review of de Souza, R. (2019). *Feeding the other: Whiteness, privilege, and neoliberal stigma in food pantries*. Cambridge, MA: MIT Press.

Jakob Mauer, LGSW, CSW-I

Walla Walla University, William Hepker School of Social Work and Sociology

Correspondence concerning this article should be addressed to Jakob Mauer, Walla Walla University, William Hepker School of Social Work and Sociology, 204 S. College Ave., College Place, WA 99324. Email: jakob.mauer@wallawalla.edu

Understanding the Impact of Neoliberalism and Racism on the Food Insecure within Food Pantries: A Book Review

In *Feeding the Other*, Rebecca de Souza (2019) argues that neoliberal ideas hurt the food insecure, thus challenging the long-held American narrative that hard work and individual responsibility are the keys to a bountiful and successful life. She identifies poor households, single mothers, and people of color as groups disproportionately affected by hunger and food instability in the United States. Through her ethnographic work grounded in social change theory, de Souza (2019) investigates food injustices in the United States and explains how neoliberal stigma marks people as bad citizens and perpetuates their food system oppression. She identifies stigma as an exercise of power. In relationship to race and gender, she notes how ordinary white men control the values and processes within food systems, marking those without sufficient resources as stigmatized consumers who must use food pantries to eat. Although some may criticize de Souza's (2019) book for focusing on food pantries, the bottom of the food industrial system, she presents the reader with valuable knowledge to critically evaluate how neoliberal ideology legitimizes entitlement failure and food injustice at the point of service. The purpose of this review is to discuss how de Souza (2019) in *Feeding the Other* highlights the narratives of marginalized consumers within food pantries while also considering areas of future discussion regarding systemic food system change.

Centering Marginalized Narratives

Past literature has focused on the voices of charity givers and volunteers within the food system (Poppendieck, 1999) and the relationship between anti-hunger groups and corporate charity (Fisher, 2017). de Souza's (2019) work adds to the food justice conversation by addressing discursive practices within food pantry spaces. She challenges readers to recognize, confront, and shift their narratives around the causes of hunger and who is hungry. In doing so, she casts a vision for reconstructing the food system towards equity. In *Feeding the Other*, de Souza (2019) centers interviews with food pantry consumers to help the reader understand clients' experiences within these spaces. Their narratives act as counter-stories to the neoliberal ideology, systems of whiteness, and patriarchal norms that beset the United States food

system. As an example, de Souza (2019) offers the story of Trinity, a Black woman client of a faith-based food pantry called Ruby's Pantry. Trinity identifies puritanical beliefs, the falsehood of the American dream, and public health debates as discourses that contribute to her stigmatization. By naming their oppression, consumers expose systems of privilege that dominant voices often obscure, replacing them with new narratives.

de Souza's (2019) work also contributes to scholarship that critiques a charity model of change, such as Janet Poppendieck's (1999) influential book arguing for the deconstruction of charity within food systems in favor of centering food as a human right rather than a gift. Additionally, Fisher's (2017) work argues that the relationship of the anti-hunger movement with corporate charity perpetuates food injustice by feeding the hunger need versus dismantling systems that cause food insecurity. In line with Poppendieck (1999) and Fisher (2017), de Souza (2019) illuminates issues caused by food-based charity, including unpredictable donations and the legitimization of distributing low-quality products to those with the most nutritional needs. However, de Souza (2019) centers on the voices of the consumers, whereas Poppendieck (1999) focused on interviews with charity givers and volunteers, and Fisher (2017) concentrated on conversations with leaders from the anti-hunger-industrial food complex. de Souza (2019) argues that charity results in the depoliticizing of hunger, making it impossible to critique the giver. For example, she states that social justice is not accomplished when "we," who are often white, middle to upper-class persons, through large donations or volunteering, give to "them." These acts and language may deepen social distances because clients are hesitant to complain and police their language around volunteers fearing that they will be restricted from vital services. Throughout the book, de Souza (2019) engages readers in reflexivity by tackling complicated food ethics and justice questions, which challenges readers to consider their roles in these food systems.

Critiques and Areas of Consideration

Critics of *Feeding the Other* (de Souza, 2019) may say that focusing on food pantries will not create widespread systemic change. Indeed, it might be that food pantries play too small of a role in the neoliberal stigma and systemic injustices of the food system. For example, even as community voices are foregrounded, there is often a concern with how to move these experiences into transformative policy changes, which, as noted by de Souza (2019), is a phenomenon rarely discussed in the literature. At the bottom of the supply chain, pantries are not directly involved in producing and implementing national or state policies surrounding distribution and nutrition access. Additionally, people in the community do not often know how policy works or effective interventions for navigating macro policy changes. Such a focus may not lead to systemic transformation, potentially wasting time, resources, and money to a futile cause while disadvantaged persons continue to have their basic sustenance needs unmet.

Although critics may contend that an inherent risk of studying food pantries is to waste time, resources, and money on the bottom portion of the food system, de Souza (2019) provides considerable arguments against this critique. First, she states that food pantries are nearest to persons who suffer from the hunger epidemic. Thus, they can be spaces where change is instituted to lessen the impact of neoliberal stigma that swirls around the hungry in these locations. Second, she argues that food pantries interact with wide social circles because they service clients, offer jobs and volunteer positions to community members, organize outreach programs, and engage with government officials. Therefore, working within this system efficiently establishes a vast network engaged in activism for food justice.

Conclusion

Each chapter provides a unique facet of oppression within food pantries, offering multiple perspectives for consideration, dialogue, and activism. de Souza's (2019) work gives the reader a list of implications for practice and policy, encouraging further research by agencies and advocates. de Souza (2019) argues that food pantries must coordinate and affirm their moral privilege as spaces that can expose systems of domination in the food system for the change to begin; privileged narratives must shift surrounding hunger and approach systemic transformation.

Feeding the Other (de Souza, 2019) is a meticulously fashioned book that illuminates the negative implications of neoliberal stigma on hungry people. Her research participants indicate that the neoliberal stigma casts them as lazy, unworthy, unhealthy, and bad citizens, effectively dehumanizing them. These internalized stereotypes may lead to poor self-esteem, self-concept, and depression, amongst many other health issues which are further compounded by their food insecurity. de Souza (2019) warns that this book might make some readers uncomfortable; however, she provides a wonderful learning experience for any reader to understand the structural patterns of injustice within the food system from the consumer's perspective rather than the charity giver. The present review contends that this approach is novel and should guide future research on food system injustice.

References

- de Souza, R. (2019). *Feeding the other: Whiteness, privilege, and neoliberal stigma in food pantries*. MIT Press.
- Fisher, A. (2017). *Big hunger: The unholy alliance between corporate America and anti-hunger groups*. MIT Press.
- Poppendieck, J. (1999). *Sweet charity?: Emergency food and the end of entitlement*. Penguin Books.

Jakob Mauer, LGSW, CSW-I, is a second-year student in the DSW program at Walla Walla University. Jakob is dual-licensed in Minnesota and Nevada --where he is currently practicing clinical social work. His research interests include LGBTQIA+ well-being, supervision, and cultural humility. Jakob hopes to pursue an academic appointment following the completion of his DSW.

The logo features a large, stylized letter 'U' in a dark red color. The 'U' is composed of four rounded rectangular segments that meet at a central white circle. Inside this white circle, the text 'UNIVERSITY of HOUSTON' is displayed. 'UNIVERSITY of' is in a smaller, grey, sans-serif font, while 'HOUSTON' is in a larger, bold, red, sans-serif font. A thin horizontal line is positioned below 'HOUSTON'.

UNIVERSITY of
HOUSTON

GRADUATE COLLEGE
OF SOCIAL WORK