International Health Trends and Perspectives

Intersectionality framework for children with special healthcare needs: A scoping review

Original Research

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ABSTRACT

Introduction: The experience of children with special healthcare needs (CSHCN) who hold multiply marginalized identities is underrepresented in healthcare research literature. Even less research investigates the impact of multiple systems of oppression on CSHCN experiences with healthcare providers, services, and systems. **Methods**: To identify gaps and areas of future research, in early 2020, a scoping review of current CSHCN healthcare literature that includes an explicit intersectionality framework or analysis was conducted. **Findings**: Based on the literature search results, there were zero peer reviewed articles within the CSHCN research literature that included a framework or analysis of intersectionality. **Implication**: CSHCN have diverse lived experiences. An explicitly intersectional approach is best suited to creating programs, treatments, interventions, and service provision that address the truly complex needs of this population within the U.S. dominant culture. Promising frameworks and future research needs are discussed.

KEYWORDS

Children with Special HealthCare Needs, Intersectionality, Population Health, Public Health, Social Determinants of Health

INTRODUCTION

The experience of Children with Special HealthCare Needs (CSHCN) who hold multiply marginalized identities is underrepresented in healthcare research literature. Even less research investigates the impact of multiple systems of oppression on CSHCN experiences with healthcare providers, services, and systems. Therefore, this study contains several seminal works (e.g., Bauer, 2014; Bowleg, 2012) that influenced the field of Public Health and the field of healthcare, but have not necessarily been applied in recent years to CSHCN healthcare research.

Children with Special HealthCare Needs (CSHCN) are defined as "those who have or are at risk of having a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998). CSHCN are not a monolithic group. They are as diverse as the rest of the healthcare population. According to the Centers for Disease Control and Prevention, 1 out of every 5 children in the United States has a special healthcare need (2019). The prevalence of special health care needs among non-Latinx Black children is 18%, which is higher than the total non-Latinx Black children population of 13.1% (Abdi, Seok & Murphey, 2020). Authors Abdi, Seok and Murphey (2020), hypothesis this disparity may be due to identification bias or other types of discrimination such as racism.

In addition, there are disparities among Latinx CSHCN depending on the primary language spoken at home. The prevalence of special healthcare needs among Latinx CSHCN who speak English as their primary language in the home is similar to that of non-Latinx White CSHCN. However, the prevalence of a special healthcare needs is lower among Latinx CSHCN who are from primary Spanish speaking households (p.11). This discrepancy may be related to

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language and cultural differences affecting assessment and diagnosis (Blumberg, Read, Avila, & Bethell, 2010). The term Latinx is used in this study to be inclusive of all possible gender identities (Torres, 2018). Latinx indicates the variety of gender identities, which include non-gender binary and/or transgender CSHCN.

Children with Special with HealthCare Needs (CSHCN) have varying levels of healthcare access, quality of services and experiences. These varying levels of access, quality of services and experiences tend to not be shared equally across the CSHCN population. Depending on race/ethnicity, gender, household income and other sociodemographic factors, CSHCN with multiple marginalized identities may be disproportionately impacted. According to Ngui and Flores (2007), for example, Black and Latinx CSHCN are disproportionately more likely to live in poverty, be uninsured, and lack a personal doctor or nurse.

These authors also note that CSHCN who are Black and, in particular, female, are more likely to have unmet mental health care needs. The intersections of being Black and female with special healthcare need(s) has implications for receiving or having access to mental health services. Ngui and Flores (2007) state that these disparities could be based on the diagnosis process and treatment of mental health conditions among girls versus boys, indicating a systemic gender bias issue. Limited changed has occurred over the past decade within CSHCN healthcare research to address these disparities. As noted by Berry and colleagues (2010),

Over the past 25 years, great gains in health care delivered to CSHCN have resulted from improved identification and classification of disabling conditions, new medical and surgical interventions, the Individual with Disabilities Education Act and the promotion of school and community inclusion programs. Despite this progress, many CSHCN do not reap the benefits as a result of socioeconomic, racial and ethnic health disparities (p.S112).

Social Determinants of Health (SDH) is a framework used within healthcare literature to examine how social factors (where people live, work, and play) may impact a person or a community's health (About Social Determinants of Health, n.d.). The SDH framework examines how these factors contribute to an individual's health and well-being, instead of explaining how these health conditions came to be in a community or neighborhood. As Raphael (2006) emphasizes, the SDH framework fails to consider the larger systemic picture that "illuminates the political, economic, and social processes by which the quality of SDH is shaped" (p.654).

Cheng, Goodman and the Committee on Pediatrics released a Policy statement (2015) acknowledging that children's developmental stages and health are influenced by "[the] larger context of services and policy" (e226). They go on to discuss how children's health trajectories are affected in the present and future by these and other outside influences. Yet despite an acknowledgement of social factors or determinants on children's health, social determinants of health within children's healthcare research remains understudied (Turney, Hedwig & Mehta, 2013) and attention to intersectionality (Crenshaw, 1989) is almost nonexistent. Social determinants of health identify the disparities based on social location and intersectionality looks at how power/systems shape social location. As Bowleg (2012) states, "multiple interlocking identities at the micro level reflects multiple and interlocking structural-level inequality at the macro levels of society" (p.1267). These connections between health and social position call for more complex analyses that use an intersectional lens to account for the multiple identities of CSHCN.

Need for intersectionality in healthcare research

Intersectionality "accounts for lived experience at neglected points of intersection—ones that [tend to reflect multiple subordinate locations as opposed to dominant or mixed locations" (McCall, p.1780, 2005). Intersectionality is a framework for understanding multiply marginalized identities and the interactions between privilege and oppression based on social locations (Crenshaw, 1989). The framework was developed by Black feminist scholars and coined by legal scholar and activist Kimberlé Crenshaw. Originally, intersectionality focused on race and gender, but its application has and can be used to examine other social positionalities as well. It views marginalized social identities as interlocking and dynamic to each other, not separate and in isolation from one another.

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If intersectional analysis was used in the Ngui & Flores (2007) study, for example, a deeper dive into systemic issues regarding gender, race, and mental health (special healthcare need) diagnoses could have been examined. Understanding the importance of intersectionality of CSHCN within the context of SDH is essential for the healthcare system to create interventions that are multidimensional, flexible to diverse populations, and examine the power dynamics of social conditions. In other words, as Johnson (2019) states,

If medicine is to maintain its authority over human problems and its role in finding solutions for those problems, it must expand its models to account for the diverse and polymorphous components of health and wellness or risk promoting partial understandings that eclipse lived experience and prevent comprehensive healing (p.529).

Existing research tends to treat Children with Special HealthCare Needs (CSHCN) as an essentialized group (e.g., white, heteronormative and middleclass). By omitting social contextual factors of CSHCN research implicitly insinuates that the CSHCN population is monolithic, with similar struggles and oppressions, striving for identical representation (Bell, 2006). Essentializing the CSHCN population "does not consider or address the rich diversity within disability communities— [for example] racial and ethnic diversity" (Bell, 2006, p.276). The prevalence of a special healthcare need varies depending on a child and family's social positionality, which can include, but is not limited to racial, ethnic, economic, and other sociodemographic characteristics.

The current study, a scoping review conducted in early 2020, investigates the extent to which CSHCN research has employed an intersectional framework. The review was guided by the question: To what extent is intersectionality being used within healthcare literature focused on Children with Special HealthCare Needs?

METHOD

Search Terms and Procedure

At the beginning of 2020, a literature search was conducted using Portland State University's Library search engine referred to as "Primo." Portland State University is part of a consortium of academic libraries that contracts with the vendor Ex Libris to provide them with a common catalog of materials using their Primo search engine. Ex Libris combines the information from individual libraries into a master list of resources known as the "Primo Central Index" or "PCI". Using Primo, with the date range of 2015-2020, the following search was conducted using the terms (Table 1): "Children with special health care needs" AND "intersectionality;" "Children with special healthcare needs" AND "intersectionality;" "CSHCN AND intersectionality;" CSHN" AND "intersectionality." This search resulted in 36 articles (Table 2). The 36 articles centered on the population of Children with Special HealthCare Needs; however, using these search terms, zero articles were returned that referenced intersectionality. Zero articles contained the acronyms CSHCN and CSHN, and the term intersectionality (Figure 1).

Search Terms

The same literature review using the same search terms was performed using Google Scholar as the search engine (Table 1); this resulted in six items with the acronym CSHCN and intersectionality within the body of the article (Table 2). Out of the six articles that appeared in the search, three were PhD dissertations and one was a graduate project (unpublished), which included the term intersectionality. One dissertation specifically uses intersectionality as a lens for analysis within the study. One of the dissertations had the term intersectionality in the Areas of Special Interest for the scholar but was not used in the study itself. Two of the dissertations used the population term Children with Special HealthCare Needs or CSHCN but the population of interest was CSHCN caregivers and/or CSHCN healthcare providers, and the third dissertation focused on African American families with a child diagnosed with Autism. In addition, the three dissertations and graduate project were completed within the last three years (i.e., 2017-2019). The other articles retrieved from the search included two peer reviewed articles, one centered on the language use of providers with autistic patients, and the other article was centered on prenatal disability diagnosis. Each of these articles used the term intersectionality within the body of the paper but were not specific to the CSHCN population.

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RESULTS

Based on the literature search results, there are zero articles within the Children with Special HealthCare Needs (CSHCN) research that include a framework and/or analysis of intersectionality. Although the term intersectionality is not used in the healthcare literature focusing on CSHCN, the search generated several articles focusing on one or two categories indicating social identities. For example, race and/or ethnicity and/or gender status are sociodemographic characteristics used within child health research (Ngui & Flores, 2007; Bennett, Rankin & Rosenberg, 2012; Chapman & Tait, 2010; Berry, Bloom, Foley & Palfrey & 2010). Much of this healthcare literature speaks to one or two sociodemographics of the multiply marginalized CSHCN to discuss the reasons behind healthcare disparities. However, these research approaches "do not consider the unique intersections between the categories or intersectional positions within a category" (Bauer, 2014, p.11). There is substantial evidence that suggests that there is more heterogeneity within groups than between groups (Crenshaw, 1991; Hancock, 2007).

In addition, the current research is missing the examination of multiple overlapping power dynamics (privileges and oppressions) within the U.S. healthcare system, and their cumulative impacts on children with special healthcare needs who hold multiple marginalized identities. Furthermore, power dynamics are excluded within the Discussion and Future Research sections of studies. Instead, studies focus on recommendations centered on behavior modification of what the patient (or patient's family) can do, or education for providers to improve their knowledge of diverse cultures.

DISCUSSION

The primary goal of this scoping review was to determine to what extent literature on Children with Special Healthcare Needs includes an explicitly intersectional analysis. Examining macrolevel oppressions reveals children of racial/ethnic minority status, children of single parent households, and children living at or below the poverty level experience the poorest health (Bloom, Cohen, & Freeman, 2009). Just as the macrolevel of oppressions are examined, so should the macrolevel of privilege. To examine oppressions, regardless of the context (micro/macro), means that there is an acknowledgment of the existence of privilege. There cannot be one without the other; oppression cannot exist without the existence of privilege. In other words, as Windsong (2016) asserts, "intersectionality as an analytic framework shifts away from a sole focus on oppression and directs researchers to take a relationality perspective that examines both privilege and oppression" (p.137). For CSHCN research to expand into the realm of intersectional analysis, a recognition of the influences of privilege on oppression should be included in healthcare research. Questions that can be used to examine how privilege has impact on CSHCN in healthcare research are: What CSHCN are benefiting from the current CSHCN research? What CHSCN families are being heard? How does the culture of white supremacy benefit some CSHCN within the context of the healthcare system? What CSHCN voices are missing from the research?

Intersectionality is derived from critical theory and includes the examination of the dynamics of power and how they affect a person's lived experiences. Children with Special HealthCare Needs (CSHCN) have diverse lived experiences and deserve a multidimensional examination within the healthcare literature to create better programs, treatments, interventions, and service provisions that address the complexity of their lives. Multiple identities should not be seen as separate or fixed, but rather as interlocking components of one's experiences and interactions within society and societal structures. Examining macrolevel barriers or challenges, along with privileges, will create a different perspective in how solutions are created, research is designed and conducted, and what type of data is collected. As summarized by Bowleg (2012), "Intersectionality provides the discipline of public health with a critical unifying interpretive and analytical framework for reframing how public health scholars conceptualize, investigate, analyze, and address disparities and social inequality in health" (p.1267).

There is a growing movement to guide intersectional healthcare research for Children with Special HealthCare Needs (CSHCN). Several scholars from different fields have written about the use of intersectionality both as a theoretical framework and practical application within research, both for qualitative and quantitative studies (e.g., McCall (2005), Hankivsky & Christoffersen (2008), Choo and

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Ferree (2010), Bowleg (2012), Bauer (2014), and Evans (2019). The remainder of this paper will discuss these potential applications to research on CSHCN.

Hankivsky & Christoffersen (2008) and Bowleg (2012) discuss the need for the application of intersectionality as a framework for population health, but within different healthcare contexts. Hankivsky and Christoffersen (2008) discuss the applicability of intersectionality within Canadian population health research, noting that Canada's healthcare research is problematic even within their universal healthcare system. Although much Canadian healthcare research currently uses social determinants of health as a framework, the research does not respond to the foundational (p.271) causes of illness and disease, and still employs the use of master categories or essentialized grouping of sociodemographic characteristics excluding multiple interlocking categories at the microlevel and structural macrolevel causes of inequality. Table 3 highlights Hankivky's and Christofferson's (2008) four areas where intersectionality is beneficial within the current healthcare research. Likewise, Bowleg (2012) identifies intersectionality as an important theoretical framework for public health within the United States healthcare system, and Table 3 exhibits Bowleg's (2012) five ways an intersectional framework benefits public health research.

Impact of Intersectionality on Research in Canadian and U.S. Population / Public Health

Intersectionality as a framework is complex, but researchers have created starting points for managing the complexity and developing new ways to conceptualize research. Researchers like McCall (2005), and Choo and Ferree (2010) identified approaches to manage some of these complexities. McCall's Complexity of Intersectionality (2005) is a foundational article for conceptualizing and managing the framework within three different categories: intercategorical complexity, intracategorical complexity and anticategorical complexity. Intercategorical complexity looks at the relationship of inequality among social groups and tries to explain or analyze the meaning between the social groups. Intracategorical complexity focuses on a particular social group at a specific intersection, for example a particular group of women of color, e.g. queer Latinx women. The last category within McCall's analysis is anticategorical complexity. Anticategorical complexity is managed by not reducing characteristics to a fixed category, but instead deconstructing the analytical categories.

According to Choo and Ferree (2010) intersectionality theory includes three main core tenets for consideration in health research; 1) group centered, 2) process-centered, and 3) system-centered. Group-centered research aims to bring in the experiences of marginalized groups who have largely been absent from scholarship. Process-centered research uses comparative analysis and a premise of relationality, and in doing so, demonstrates the context and comparisons of different intersections in order to better understand the structural and organizing processes of inequality. "System-centered research 'sees gender and race as fundamentally embedded in, working through, and determining organization' of systems of inequality" (Choo & Ferree, 2010, p. 135).

Evans (2019) provides examples and possible solutions for incorporating intersectionality within quantitative modeling, which includes structural determinants. Green et al. (2017) provide two different directions for incorporating intersectionality within quantitative research in epidemiology by integrating intersectionality with multilevel analyses of contexts within which intersectional identities exist (e.g., school, neighborhoods, states) and second, in Structural Equation Modelling (SEM). Both directions try to incorporate and measure the power structures within which groups (or communities) live, work and play.

Windsong (2016) provides an exemplar and outline for translating intersectionality into qualitative research, specifically within qualitative in-depth interviews. They discuss how they integrated core components of intersectionality while developing their research design and interview questions for the study. Questions of complexity emerged around "how to incorporate intersectionality while allowing participants the opportunity to share their own lived experiences" (p.143). They discuss the often-dual nature of qualitative research, which involves either a design that directly addresses theoretical concepts or a design that allows for concepts to emerge without prompting. Windsong (2016) ultimately chose to directly speak to intersectionality by using questions

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that address intersectional concepts. Their discussion of pitfalls and challenges provide lessons for future qualitative intersectional research.

A recent working document by the University of Minnesota and the Minnesota Department of Health titled *Intersectionality and Trauma-Informed Application for Maternal and Child Health Research and Evaluation: An Initial Summary of the Literature* (2019) reveals a critical (and needed) shift within public health and an acknowledgement of the need for an intersectional framework within the Children with Special HealthCare Needs (CSHCN) research. The researchers conclude their study with five approaches to public health research and evaluation: 1) positionality matters, 2) reconsider methods and approaches, 3) integrate reflexivity, 4) acknowledge systems cause harm, and 5) take action for healing and justice (p.16). These five approaches to future research recognize that CSHCN and their families have varied lived experiences, there are broader macrolevel implications to micro and mezzo level health outcomes, and there is a need to approach research with more complexity. In addition, the researchers highlight the need for self-reflexivity among researchers so that researchers identify their own social position and recognize how their values and ways of knowing influence their research.

CONCLUSION

The primary goal of this review was to investigate the extent to which CSHCN research has employed an intersectional framework. By reviewing the existing healthcare literature regarding CSHCN and intersectionality, this review established that there is a gap in the literature that needs attention. In order to broaden current CSHCN healthcare literature to be inclusive of the most marginalized CSHCN, a shift in traditional research paradigms needs to occur.

Instead of essentializing all Children with Special HealthCare Needs (CSHCN) in healthcare research, the use of a critical lens such as an intersectional lens, could prompt researchers to ask different questions and hopefully create a counternarrative in their work. Contextual factors matter within healthcare research and using traditional research designs and methodologies will not capture the broader mezzo and macro considerations. Researchers must examine what has been accomplished, who it has benefited, who has been left out, and what is still needed to more effectively serve and include the broader population of CSHCN who have been historically invisible.

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Table 1: Database Search Terms

Database	Years	Search terms
Portland State University Library-Primo Search Engine	2015-2020	"Children with special health care needs" AND "intersectionality"; "Children with special healthcare needs" AND "intersectionality"; "CSHCN" AND "intersectionality"; "CSHN" AND "intersectionality"
Google Scholar	2015-2020	"Children with special health care needs" AND "intersectionality"; "Children with special healthcare needs" AND "intersectionality"; "CSHCN" AND "intersectionality"; "CSHN" AND "intersectionality"

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Table 2: Search Results

Type of Article	Article Reference	Population	Methods	Intersectionality Theory
Peer reviewed	Como, D. H., Floríndez, L. I., Tran, C. F., Cermak, S. A., & Stein Duker, L. I. (2020). Examining unconscious bias embedded in provider language regarding children with autism. *Nursing & health sciences*, *22*(2), 197-204.	Dental providers of children with autism	Part of a larger mixed-methods, sequential, explanatory design in which qualitative descriptive data were collected and analyzed	Intersectionality referenced in the literature review, not used as a theory for the study.
Peer reviewed	McKinney, C. (2016). Selective abortion as moral failure? revaluation of the feminist case for reproductive rights in a disability context. *Disability studies quarterly, 36*(1). http://dx.doi.org/10.18061/dsq.v36i1.3885	Feminist scholar commentary on abortion law.	N/A	The term intersectionality was used within a quote in the article. Intersectionality theory was not used in the research itself.
Dissertation	Davis, C. (2017). *Do characteristics of children and families influence reported caregiver burden?: a secondary data analysis of the 2009-2010 national survey of children with special health care needs.* [Masters Thesis, Smith College, Northampton, MA]. Smith ScholarWorks: https://scholarworks.smith.edu/theses/1886	Caregivers' of CSHCN	This quantitative secondary data analysis of the 2009-2010 National Survey of CSHCN uses a cross-sectional design	Uses intersectionality theory throughout the research process (i.e., literature review, analysis).
Dissertation	Ngo, C. L. (2017). *Experiences of pediatric parenting stress and family support for caregivers of children with special health care needs or developmental disabilities* [Unpublished doctoral dissertation]. University of Oregon.	Caregivers of CSHCN	Quantitative descriptive research design	Intersectionality was used to describe authors research interest.

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Dissertation	McCoy, A.D. (2018). *Autism spectrum disorder diagnosis from the African American parents' perspective* [Unpublished doctoral dissertation]. The University of Texas at Austin.	African American parents of autistic children	Qualitative case study	Discusses intersectionality in *Discussion* section.
Graduate Projects (Non-thesis)	Bagan, R.J. (2019). *Art therapy for differing abilities: Self-advocacy in communities-of-care.* [Unpublished, Graduate Projects (Non-thesis)]. Concordia University of Montreal, Quebec, Canada.	Art Therapist working with people with disabilities	Bibliographical qualitative research design	Intersectionality referenced in the literature review.

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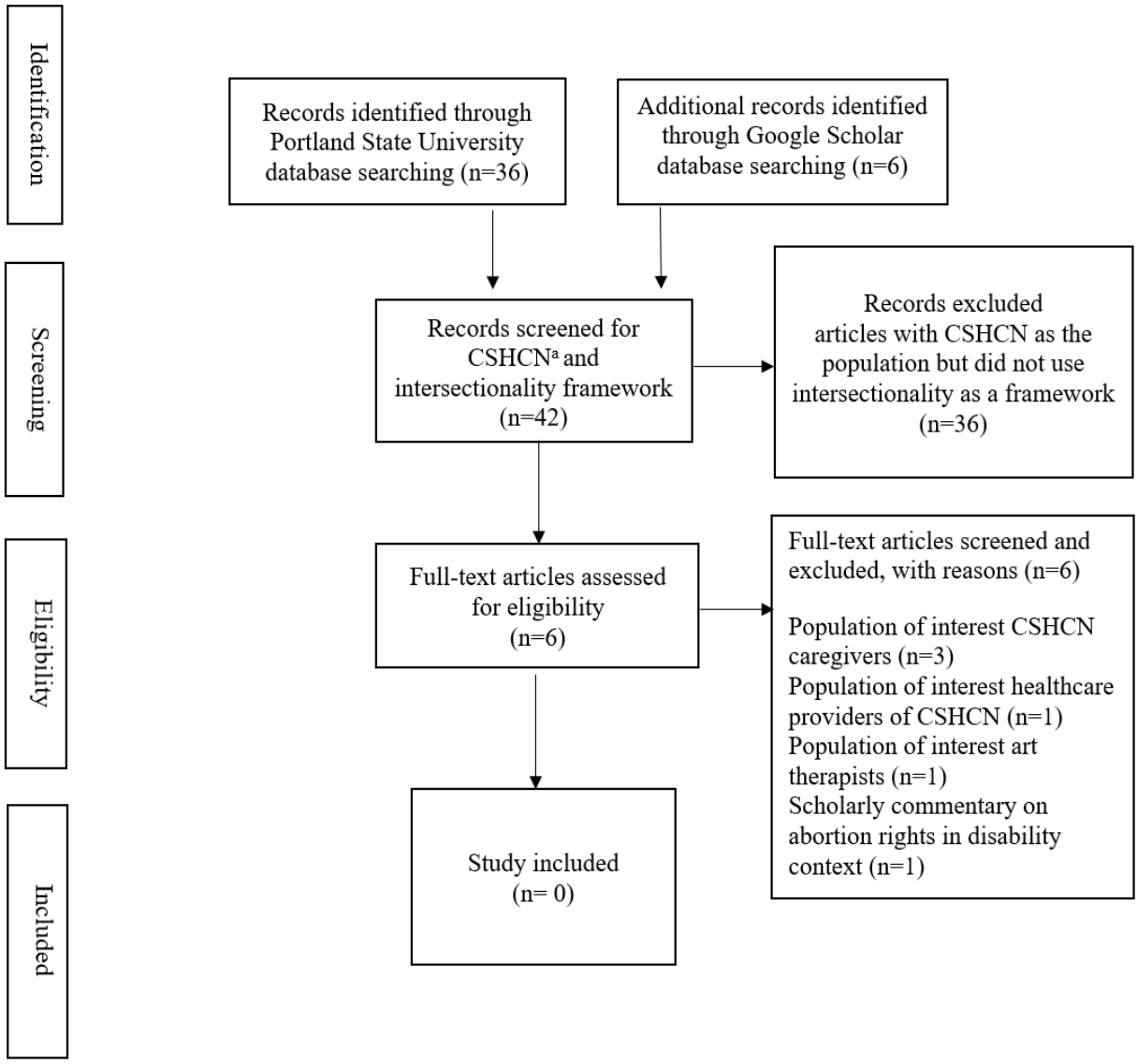
Figure 1: Flow Diagram of the Scoping Review Process



Note. [a] Includes all variations of the term Children with Special HealthCare Needs (CSHCN).

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Table 3: Impact of Intersectionality on Research in Canadian and U.S. Population/Public Health

Hankivky & Christofferson	Bowleg
1) "intersectionality interrogates the relationship and meaning between different social categories and reveals power dynamics" (p.275);	1) provides unifying language and theoretical framework to facilitate a cohesive body of empirical and theoretical knowledge that could inform policy, practice, and interventions (p.1271);
2) intersectionality moves beyond the stagnant assumption that health outcomes are "caused by a set number of contributing causes" (p.276) and acknowledges that multiple factors are always at play;	2) prompts public health scholars to conceptualize and analyze disparities and social inequalities in complex and multidimensional ways that mirror the experiences of the populations who have the most adverse health outcomes (p.1271);
3) intersectionality does not use an additive approach, instead it "seeks to uncover the convergence of experiences, including multiple forms of discrimination and oppression" (p.276);	3) focuses on the macrolevel social-structural factors moving beyond the microlevel on health, which will facilitate the development of structural level interventions most likely to affect fundamental causes of social inequalities in health;
4) intersectionality is centered within critical theory, which has social justice as a central tenant.	4) takes the experiences of historically marginalized populations and centers them to facilitate and inform health promotion messages, interventions and policies (p.1272);
	5) allows examination of multiple interlocking social identities across several categories beyond race and gender (p.1272).

Note: Hankivky and Christofferson (2008, pp. 275-278); Bowleg (2012, pp.1271-1272)

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