1. SUMMARY -
Over the past two decades, neo-liberal governance strategies in Canada have resulted in major funding cuts in health and long-term care, while at the same time encouraging individual responsibility for health and care arrangements. As part of the broader context of neo-liberal restructuring, these strategies have set the goals of quality care for recipients against those of work quality for care-providers. Personal carework, the non-medical tasks that assist people with everyday activities (i.e., bathing, eating, and related housekeeping), has been particularly vulnerable to restructuring resulting in major shifts in how personal care is funded, delivered, and organized. Changes in structural factors arising from restructuring and its accompanying fiscal and social policies intersect with social inequalities (i.e., race, citizenship, gender, and ability) to pit vulnerable groups against one another as they compete for funds, autonomy, and quality of life. Despite their harmful impact, these factors are rarely considered in policy or research. Without a clear picture of how various structural factors shape the individual relationship between providers and recipients of care, we are unable to achieve both quality care and quality work. This study will draw on gender, disability, and work scholarship to determine how structural factors shaped by neo-liberal policies intersect with social inequalities to affect the relationship between recipients and providers of care. Specifically, it will examine the relationship between adults with physical disabilities and their paid, in-home personal care providers in Toronto (where most providers are immigrant women of colour) to understand how each negotiates quality care and quality work.

In Ontario, debates over shifts in carework have been intense. Disability activists argue that good care requires programs that give individual disabled people more control via direct funding, while unions argue that this leads to privatization and the erosion of good jobs. Disability scholars argue that community-based models provide more choice in how care is provided, while work scholars find that flexible modes of service organization bring insecurity to paid workers since it is difficult to unionize workers in flexible employment. Gender scholars claim that the shift of care from institutional to community and home-based programs, coupled with funding cuts, reflects a devaluing of carework. Although these literatures suggest socio-political impact on recipients and providers, the extent to which structural context informs the relationship between recipients and providers has not been explained.

The primary objective of the proposed research is to determine how the restructuring context affects the “carework relationship,” or the ability of care recipients and providers to negotiate quality care and quality work. The term “restructuring” denotes changes in economic, political, and social contexts in response to globalization (Neysmith 2000:1; Bakker 1996). In this study, I use this concept to contextualize and understand the impact of shifts in structural factors including: funding levels and funding mechanisms for care; employment status of the care provider; the existence and nature of collective supports for care recipients and providers. Added to this analysis is a focus on how social inequalities of race, citizenship, gender, and ability intersect with structural factors to shape the carework relationship. Using qualitative, comparative methodology, I investigate the carework relationship through interviews with 45 dyads of personal care recipients with physical disabilities and their paid care providers under three models of care. The models correspond to three provider employment statuses, identified in previous research: The Agency, Self-Managed Care, Informal Sector.

As the first in-depth Canadian study of its kind, this research will make a significant contribution to scholarship on: 1) gender and care by incorporating disability as a social location that intersects with gender, class, race, and immigrant status, to shape the carework relationship; 2) the social construction of disability by placing personal care within the broader restructuring of long-term care; 3) work by demonstrating how quality work and care are linked. The study is a stepping-stone to a more general understanding of changes in the post-industrial political economy and society in which the disjuncture between industrial labor regulation and service sector employment is widespread in many types of work, and carework reflects increasing neo-liberal state policies and practices. The findings will be disseminated in journals tailored to a general sociology audience, those directed to the interdisciplinary sub-fields of gender, work and disability, and in a clear language report to policy audiences.