Unhinging the Assumptions Within Independence

Toward a Broader Conceptualization of Diversity and Difference in Home Care

AMANDA M. GRENIER
SCHOOL OF SOCIAL WORK, MCGILL UNIVERSITY

In recent years, use of the term *independence* has proliferated in the field of health and long-term care.[1] Originally associated with the normalization and de-institutionalization movements, use of this term has extended into gerontology and policy. Emphasis on demographic transition[2] of older persons and the associated health care costs have brought aging and cost restriction of care for persons considered dependent[3] to the forefront. At the same time, policy and service provision is being altered dramatically. Current health and long-term care policy efforts concentrate on balancing the *independence* of persons requiring services with the costs of providing these services.

While efforts to measure, promote, and increase *independence* dominate professional and public debate, the term has been taken for granted; there is little consistency with regards to an accepted meaning or application, instead, definitions and conceptualizations vary according to context and situation. Despite its policy significance, there has been little attention to uncovering the underlying values, assumptions and subtle meanings of using the term *independence* in relation to older persons with disabilities[4] within home care.[5] This poses problems both for those concerned with discourse as well as those concerned with demonstrating effectiveness and efficiency of service- it is difficult to measure an unconceptualized term.

At this time, public debates and efforts focused on service provision continue to include the term implicitly in numerous documents without explication of the meaning, nor consensus about what the condition of *independence* should look like in home care. As such, an absence exists at both the conceptual and implementation levels.

Context of Care: Response to Dependent Persons

Social historical transitions provide clues to understanding current issues, debates and social responses. A brief exploration of the context of care demonstrates how policy developments within the Canadian welfare state resulted in the current emphasis on *independence.* Similar to the United States and Britain, persons requiring care in Canada were labeled dependent, and emphasis was placed on determining appropriate responses to them (Chrichton and Jongbloed, 1998). In recent Canadian history, the response to dependent persons experienced three main shifts, which correspond with the establishment of and retreat from the welfare state. These transitions include the move from the charity model to public responsibility within institutions, the move from institutional to community care,[6] and the move from community care to a system of managed home or ambulatory care. Prior to 1940 and the development of the welfare state, dependent persons were cared for within the charity model by family, parish[7] and poorhouses (Armitage, 1973). In this model, older persons and persons with disabilities were categorized as the deserving poor in contrast to non-deserving/able-bodied persons requiring assistance. From 1940 onward, the response to dependent persons became public/state responsibility; Canada, along with the United States and Britain addressed the problem of unequal resource distribution by setting up comprehensive welfare states (Chrichton & Jongbloed, 1998). Persons identified as dependent were segregated into public institutions; older persons were cared for in homes for the aged.

Segregation and institutional care, however, were soon called into question. From the establishment of the welfare state in 1940 until the late 1970s, the normalization and independent living movement gained momentum (Sarage, 1998). Fighting against abuses and the institutional model, activists popularized the terms *independence* and autonomy which called into question the construction of disability as dependence, revealed the structural oppression of disabled persons, exposed institutional abuses, and proposed a new model based on rights (Morris, 1991). These rights-based movements, which were based on recognizing the worth and decisional capacities of individuals with disabilities, resulted in the recognized need for community care and initiated the general de-institutionalization movement of all persons identified as dependent. Shifts in service provision began in the 1960s, and by the 1980s there was a major transition from institutional to community care. From 1980 forward, however, Canada, along with Britain and the United States questioned their social organization and financial commitments and began what has been labeled the "retreat from the welfare state" (Chrichton and Jongbloed, 1998). This transition to community care during a period of cost restriction and retreat from the welfare state had a direct impact on both the responses to dependent persons and public debate. The primary result was a poor implementation of community care, however, a "crisis rhetoric" which paired the increasing numbers of older persons with social problems and the drain of public resources also developed (Minkler & Estes, 1991). This "overselling of demographic crisis" (Gee &Gutman, 2000), resulted in public debate about the burden of "non-productive" persons[8] which included older persons and persons with disabilities.

In response to the concerns about increasing costs, emergency room overcrowding, and criticisms of a poorly implemented community care (Joubert, Laberge, Fortin, Paradis, and Desbiens, 1991), the final policy shift in response to dependent persons was toward a system of managed home or ambulatory care (1980 to present). Legitimized by the earlier mentioned crisis-rhetoric about increasing costs, care for dependent persons in Canada and Britain shifted from rights based community care to "managed care" administered by case managers (Dean & Ellis, 2000; Neysmith & McAdam, 1999). Within this third transition toward ambulatory care, discourse about dependent persons took on business rhetoric of management and cost control. The rights of the dependent client became overshadowed by obligations of the independent "consumer" and terminology such as "partnership" emerged (Joubert et al., 1991)—the policy emphasized decreased involvement of the state and increased family, neighbour, and community responsibility. It was during this final shift to managed care, where current conceptions of promoting and maintaining *independence* as they are now articulated surfaced. Considering the social context of cost restriction and retreat from the welfare state, combined with notions of dependent persons as undeserving and a public burden, as well as the new focus business rhetoric, it is striking that a rights-based term such as *independence,* continued to proliferate. Taking the third transition as evidence of the movement from universal support to a system of targeted or managed risk, it seems that the term *independence* was appropriated into the context of managed care, where the meanings and conditions are quite different from those within the earlier rights-based movements. Prior to exploring the underlying assumptions of *independence* as currently conceptualized in home care, the literal definition of *independence* requires clarification.

Defining and Contextualizing *Independence*

A keyword search conducted in varying social science search engines reveals that the context and use of the term *independence* ranges from political freedom, to rights for persons with disabilities, and connections with wage labour. In these contexts, *independence* seems to involve intersecting notions of rights, productivity and freedom from subordination. While varying uses and subtle nuances within the meaning of *independence* were also reflected in the 2nd Edition of the *Oxford English Dictionary* (1989), the general definition of *independence* is:

> The condition or quality of *being independent;* the fact of *not depending* on another (with various shades of meaning; see adj); exemption from external *control* or support; *freedom* from subjection, or from the influence of others; *individual liberty* of thought or action. [emphasis mine] (OED, 1989)

The nuances of not being dependent that exist within the general definition are made explicit in the definition of *independence*[9] as an adjective. As expanded in the *Oxford English Dictionary* 2nd Edition (1989), "not depending on another" means:

> *Not* dependent or having to *rely on another for support or supplies.* Not dependent on any one else for one's living; not needing to earn one's livelihood; possessing a *competency.* Thinking or acting, or disposed to think and act for oneself. *Refusing to be under the obligation to others;* having a *self-respect,* which declines *unearned assistance.* [emphasis mine] (OED, 1989)

Defined as such, the literal definition provides a point of departure to explore the underlying values and implications of using *independence* within the current context of care. To start, the meaning of *independence* reflects and is reflected in the context of modern discourse. Specifically, the definition of *independence* is situated within the discourses of western modernity and twenty-first century capitalism where the individual subject is constructed as a responsible, productive, contributor to the state. The general definition establishes an obvious dichotomy between *independence* and dependence;[10] within the definition, the negation of dependence is clearly linked with notions of control, freedom, individual responsibility and productivity. To be considered *independent,* the individual subject must achieve control and freedom. Within the current social order, control and freedom are achieved in relation to individual responsibility, labour contributions, or independent wealth.

While achievement of control and freedom may be less contestable in relation to the independent worker or independently wealthy citizen, the clarification of the adjective independent is helpful in understanding how *independence* may be problematic for older persons with disabilities who need or require care. The achievement of independence is not an independent or autonomous state of being, but may be achieved only through distinction or separation from the control or reliance on others for support or supplies (OED, 1989). Independence is connected with tangible support or supplies as well as moral values of competence, deservedness (e.g., unearned), and self-respect seen in the development of social response to dependent persons. This connection between personal autonomy of the individual subject (e.g., thinking and acting for oneself) and deservedness (unearned assistance) is made explicit in the last line "having a self-respect, which declines unearned assistance" (OED, 1989). When placed within western modern discourse, the notions within *independence* evoke many questions in relation to older persons with disabilities. For example, questions surface regarding the social value of past contributions of previously productive workers, recognition of humanistic contributions, as well as contributions in kind (e.g., caregiving). Similarly, the dichotomous position of *independence* and dependence that include connections to control and freedom also bring about questions for older persons with cognitive impairments. Does the definition of independence imply absolute control and deny moments of interdependence throughout the life cycle? Does this definition position service-eligible older persons with disabilities as incompetent and lacking self-respect? Under what conditions is assistance considered as earned?

The discourse on *independence* and the inherent contradictions within the current context of twenty-first century capitalism have specific implications for older persons and persons with disabilities. The largest of which is the situation whereby capital wants to pay the social costs (i.e., pensions) but does not want to contribute to these costs via taxation (Leonard, 1997). This contradiction creates both differences in the way *independence* is conceptualized depending on group status or social location, as well as stigmatization based on moral discourse about deservedness and self-respect. In this context, bourgeois *independence* is considered freedom from dependence on the relations of production which are exploitative and cause alienation, while *independence* for dependent/non-productive persons is the avoidance of the financial assistance/services which are the social costs of the relations of production (Leonard, 1997). Thus from the literal point of view situated within the current social order, although *independence* differs depending on social location, for dependent persons, *independence* is established as the ideal and dependence as the negative and stigmatized situation to be avoided. The connection between means (e.g., income) and *independence* when combined with expectations of individual responsibility, western productivity, and moral values, blame the dependent person and maintain his/her status as undeserving. As such, *independence* seems problematic when used to describe the qualities of a person requiring assistance. Before explicating these values further, however, it is important to understand how the literal definition and implicit discourse has been applied into practice within a home care policy.

Use of the Term *Independence* in Home Care

Using the home care policy within Quebec as an example,[11] this section moves beyond the literal definition to consider how *independence* has been interpreted and applied in practice. Although it is clear that the term *independence* as it is currently conceptualized within the context of managed care, including cost restriction, has a different meaning than within the earlier rights-based trend of community care, current policy and practice do not clearly state what this term embodies. The meaning of *independence* espoused in Quebec home care is not explicitly stated, however, it seems to be used in three main ways: as a guiding value for the policy, to determine eligibility criteria or access, and finally as an outcome measure.

Independence: A Guiding Value for Home Care

The first line of the policy on home care reads: “A large number of people with a temporary or permanent disability wish to remain at home in their community for as long as they can, leading as *independent* life as possible and taking responsibility for themselves” (Quebec, 1994, p. 1). In this statement, which sets the tone and rationale for the document, *independence* and the notion of home or community are established as hopes/desires of persons with a temporary or permanent disability. There is an appeal to the notion of home and community, and an implication that a person with a disability may live an independent and satisfactory life within these settings. Not only does this statement connect *independence* to the notion of home and community, but implies that this document and the policy behind it encourage choice and support the wishes of persons with disabilities. Drawing connections between the application of the concept and earlier transitions, it may be said that the first stanza of this phrase seems to reflect the rights-based sentiments of support, choice and responsibility. On first reading, and on the social level, the use of *independence* as a guiding value for home care seems to respect the desires of persons with disabilities.

At the same time however, this use of *independence* reflects appropriated language which in the current context of care, establishes connections with modern western elements of choice and individual responsibility and lends itself to the new business rhetoric within care. Without trying to delineate the differences within these discourses, attention will be drawn to the significant absences within the opening stanza which have implications for interpretation. The word *care* or *support* are absent, as is an explication of what is meant by responsibility. The inclusion of care or support in this statement would represent a commitment to care, implying an acceptance of need and support, as well as a commitment to support persons with disabilities. The second major absence is the context in which responsibility is interpreted. Although this use of *independence* as a guiding value seems to involve elements of choice, the connections between *independence* and taking responsibility for themselves seems to imply something other than choice. In the context of twenty-first century capitalism including cost restriction, retreat from the welfare state, and the new managed care, it would seem that “taking responsibility for themselves” could easily be interpreted as the retreat of government support, justification for non-intervention, and a move toward Margrit

Eichler's (1997) notion of "family-based care" in which the family (i.e., woman) provides non-remunerative care. As such, choice and responsibility under the conditions of managed care become very different than within the earlier rights-based movements. *Independence* as a guiding value for home care is situated both within social rights of choice and support as well as problematically connected with competing rights-claims between groups, discourse on non-productivity, as well as managed care discourse which has implications for older persons and persons with disabilities.

Determining Eligibility: Dependence As Access

The terms *independence* and functional *independence* are both used within home care without clarification of the differences between the two. It seems that the use of *independence* in isolation represents the remnants of earlier social or rights-based sentiments (i.e., rights, autonomy and choice) although appropriated, while the use of functional *independence,* which focuses on limitations, seems to play the largest part in determining eligibility and restricting access to services.[12] Service eligibility is determined by classification within the target population, level of functional dependence according to a standardized scale, and need. In general, the target population for services includes "Anyone, regardless of age, who presents one or more temporary or permanent disabilities, the cause of which is physical, social or psychological, and who should receive part or all of the service he requires in his own home" (Quebec, 1994, p. 6). As such, the policy frames eligibility in global and inclusive terms, recognizes temporary or permanent disabilities as progressive, and both recognizes and expects decline (Quebec, 1994, p. 6).[13] While a central concept is the ability to look after oneself, care providers and case managers assess the level of care needed to prevent institutionalization. To achieve this, eligibility is determined using a standardized evaluation tool which is functional in nature;[14] persons seeking home care are ranked according to the severity or level of loss of *independence.*

In this sense, it is not the global right to receive care that defines eligibility and creates access to service, but restrictions according to the level of functional dependence. Implicit within the use of functional *independence* is the consideration of cost restriction, where services are provided only to those most in need;[15] priority is determined by urgency of the need, degree of support by family and friends, and socio-economic level. Standards of access are set quite high and are tied to medical notions, making it difficult for persons to gain access to services based on maintenance criteria or social needs; further, research suggests that resources are insufficient to meet policy obj ectives (Lesseman & Nahmiash, 1993). As such, the eligibility criteria seems to exclude persons based on a hierarchy of disability, impairment, limitation, and decline. Similar to the formal definition, functional *independence* is applied as the avoidance of dependence brought on by a progressive loss of functional capacity—disability is paired with loss and limitation, and need is reduced to the measurement of the severity of bodily disability. Recognition of capacities and lower level/maintenance needs are often absent within the conceptualization and measurement of functional *independence* within home care.[16]

Independence: Criteria for Measuring Service Outcomes

Functional *independence,* client and agency participation, and judicious and efficient utilization of health and social resources, form the triad of goals for home care services. (Quebec, 1994, p. 15) Connected with managed care ideals of partnership and efficiency, functional *independence* becomes the implicit criteria for judging the outcome of service. In the managerial context, which emphasizes effectiveness and efficiency, goals are considered measurable outcomes. *Independence,* however, is a difficult concept to measure. Although the use of functional *independence* may be useful to assess and restrict eligibility for health-related service (e.g., physio) within a risk-based model, considering the expectation of decline, it seems a rather unrealistic goal to assume that service-eligible persons with high levels of functional impairment will surpass these obstacles. In typical goal setting strategies, this matching of dependence as eligibility and *independence* as outcome seems logical, yet in health and long term care, the matching of the goal and outcome presents inherent contradictions as well as problematic conceptualization. The achievement of *independence* depends on how the concept is defined. It would not seem realistic for a person with a chronic degenerative condition to be completely independent when *independence* is defined as not depending on the support of others. Here we see how notions of productivity and individual responsibility are caught up within *independence.* Further, questions must be raised on whether it is possible or ethical to place human lives under the lens of financial audit. Instead, a humanistic perspective has been suggested opposed to an "human economy" perspective, which measures effectiveness and efficiency in dollar value only (Clark, 1993, Gee, 2000). Conceptualization of *independence* as productivity, responsibility, and self sufficiency as intended outcomes within care has the potential to subject human lives to unrealistic and unethical standards, shape services in an incremental fashion thereby failing to achieve service intentions, and exclude the lower-level needs which may in-turn prevent later crisis. Drawing attention to how *independence* operates in practice raises questions about the underlying values, usefulness in relation to home care, and implications of using *independence* in relation to older persons with disabilities.[17]

Exposing the Underlying Values

Situating independence within discourses of dependence and productivity as well as conceptions of the body, this section makes explicit some underlying values and meanings of using *independence* within home care, and how these values are problematic for older persons with disabilities. Discussions will focus on the stigma of dependence, the concept of measuring bodies at risk, and mythical control, which includes the denial of disability and difference.

Stigma of Dependence

For years now, authors have critiqued the matching of dependence, disabilities, and burden (Walker, 1982). However, the current definition and use of the term *independence* contextualized within western modern discourse of avoiding dependence on the state, maintains the notion that older persons with disabilities who require publicly funded services are deemed less valued. The use of *independence* involves an illusion of control and choice, especially when applied in home care as an overarching value or moral guide. The illusion of choice is often evident in the consumer rhetoric used to appeal to public debates, indicating that home care represents choice.

Yet, instead of representing the control to choose services or make decisions, which is advocated by disabilities rights perspective, control and choice within home care are grounded in western modern discourse which positions persons with disabilities as having a lack of control, as non-productive, and therefore a financial burden. In relation to older persons with disabilities, assumptions about need and cost of support intersect with attitudes about age. According to Jenny Morris (1997), persons with disabilities confront the two main stereotypes of being dependent and grateful or demanding and undeserving. While, these stereotypes also apply to older persons, stigma of decline for being past “productive” years and blame for poor financial planning also play into the discourse about older persons. Although anti-ageist and anti-ablest arguments are often made separately, intersecting discourses about *independence* and dependence, which include the restriction of public support, maintain and support the stigma of dependence for older persons with disabilities.

Bodies at Risk

In addition to maintaining a stigma of dependence, the use of functional *independence* within home care fragments the bodies of older persons with disabilities, creates a hierarchical classification based on bodily impairment and risk, and subsequently restricts access to services in the interest of cost. In both gerontology and social policy, the normal body has been placed in opposition to the abnormal body; gerontology has tended to study, classify, and pathologize the older body (Katz, 1996), while, social policy has focused on discriminating between functional and non-functional bodies to determine eligibility (Dean and Ellis, 2000). Measuring *independence* or functional impairment to determine eligibility or access to services, when contextualized within service restriction and considered as a medicalized notion has serious implications for older persons with disabilities. The current conceptualization and measurement of functional *independence* seems to deny differences amongst bodies, disability and decline. Framed in terms of impairment and inevitable decline, older persons with disabilities are defined only by their declining bodily capacities or absence of functional ability. As such, although the older person and their families are often involved in service planning, and may be given the space to discuss their needs, they often must fit into service classifications of decline and available services.

Functional *independence* as risk determined through assessment of impairments not only partializes the experiences of persons through body parts, but creates a hierarchical classification of disability according to medical criteria, in which the more-able disabled persons are excluded from services. This hierarchical classification creates divisions amongst persons with disabilities based on an avoidance of the stigma associated with death/decline. Further, the notion of restricting services is contrary to notions of support and care. This notion of bodies at risk however, does not exist within a vacuum. Within the current context, risk for older persons may refer to the risk of death accompanied by stigma of devalue, as well as the risk of increased costs. As argued by Nancy H. Harding and Colin Palfrey (1997), in the era of medicalization, the search for a cure for aging is ultimately a search for the cure to death. Age then becomes, as Sally Gadow (1996) says, the "death rehearsal," where aging is automatically paired with dependence, disability and decline until death. It is these ideas which pair age, disability, decline, and death with risk, need, and cost that are problematic. To restrict costs and control demands, eligibility requirements for home care are set high and difficult to attain. In the current context of service restriction, eligibility is limited through discriminating amongst varying bodies at risk. Further, although the rationale for risk is often stated as the avoidance of institutionalization, the aging body undeniably exists within a larger social context of productivity, which devalues the shift from productive worker to unproductive, dependent person.[18] As such, functional *independence* and the ranking of bodies at risk perpetuates the dichotomy of body and mind, structures inequality by restricting access and perpetuates the stigma of both age and disability.

Mythical Control and the Denial of Disability and Difference

Within home care, notions of control are explicitly presented as the way to achieve independence. *Independence* as control however, is not articulated in the disability-rights sense of empowerment, choice, and control (Wincup, 1998), or "control in principle" (Magnus Reindal, 1999). Instead, control seems to be articulated in terms of Susan Wendell's (1996) notion of the "myth of control" or rational model of "overall control" (Magnus Reindal, 1999)[19] which refers to the "widespread myth that the body can be controlled" (Wendell, 1996, p. 93). This myth of control maintains the Cartesian distinction between mind and body and regulates that one must present the individual self as strong despite a weak body. This myth indicates that all persons should have control of their bodies at all times, and positions persons with illness or disability as unable to exercise control, or less controlled, and therefore, less valued. Implicit in this myth of control are discourses of normalcy which promote the avoidance of disability and decline. The myth of control ignores and denies moments of interdependence in life. Within the current context, this need for *independence* at all times is regulated by market value; *independence* is not reinforced for those who earn a wage and are therefore considered productive.

In contrast, the older person's moments of dependence or interdependence are viewed as an absence of control and deemed negative as a result of their position in terms of labour and productivity. In addition, the underlying myth of control within *independence* in home care, buys into the dichotomy of body as pathological and self as normal. This notion of control over the body is problematic in situations of expected decline. As such, there is a contradiction between expecting control and *independence* and the experience of decline and need. As such, the mythical notion of control within *independence* perpetuates harmful notions about being older and having a disability.

Further, the use of *independence* in home care is located within a particular ideological discourse, which denies differences amongst persons with disabilities and between varying social locations.[20] Undeniably, persons with disabilities have real needs which are related to their disability. These may be in the form of standard claims for access, but may also include specific individual needs. *Independence* connected with the myth of control does not recognize the existence of systemic issues such as inaccessibility and institutional ableism. The mythical control emphasizes control of the individual subject, and therefore denies the need for public support or interdependence. As such, western values of the individual subject and individual responsibility within *independence* are placed as the norm; possible social locations such as the place of some elders in the Aboriginal community or grandparents within Asian communities are ignored and replaced by dominant notions of the older body at risk. In current context of risk-based restrictive services, available services may not account for differences in social location, nor meet the individual needs of the person. Changing notions of state combined with restricted notions of eligibility pose particular issues for older persons with disabilities; older persons who do not meet functional criteria may be excluded from services. As such, the right to support has been overlooked. The use of *independence* as control is situated within a dominant western discourse that denies both disability and different realities/experiences of older persons with disabilities that dependant on social location.

What Should Independence Look Like?
A Broader Conceptualization of Diversity and Difference

Having explored the meaning, practice application, and implications of using the term *independence* in relation to older persons with disabilities, it is clear that *independence* in the current context of managed care and cost restriction is a problematic notion that cannot continue to be used as is. *Independence* as articulated in home care is situated within a western modern discourse and is packed with underlying assumptions that carry the implications of stigma, myths of control, and hierarchical risk-provided services for older persons with disabilities. *Independence* is more problematic when differences within disability and social location is considered. If indeed the rising number of older persons does result in increased demands for service, the use of *independence* for older persons with disabilities has the potential to impact on the lives of many persons. As such, I am cautious of making choices that further marginalize diverse persons with disabilities, and wish to open a debate concerning how concepts, goals, outcomes, and values in homecare should be articulated. The argument below intends to highlight the tensions and struggles of conceptualizing a term and conditions which include difference and diversity and are thus relevant for diverse older persons with disabilities.

Although *independence* has become problematic within the current context, it was not always so. The term *independence* offered much success to the disability rights movement when conceptualized as choice and access to rights. Considering Judith Butler's (2000) suggestion to move between the language critique and struggles of everyday life, although the use of *independence* in homecare raises many questions for older persons with disabilities, it also has the potential to inform change when articulated differently. As I lean toward reconceptualization of *independence* along a continuum of acceptable conditions, I am aware of the risks that since *independence* is inseparable from the current context, there is a potential to both sustain ablest policy and/or fall short of making much needed change. In the past, authors have suggested the replacement term interdependence as a more inclusive and humanistic term (Leonard, 1997; Magnus Reindal, 1999). While I also suggest a more human understanding and would agree with the fundamental changes inherent in replacement, I am skeptical of the position of interdependence within the dependence/ *independence* debate. Further, I am not sure that the term interdependence within the current context would avoid the continued movement from state support which assumes that women will provide care services unrecognized and without compensation (Baines, Evans, Neysmith, 1998). As such, I will articulate how notions of human need, right, diversity, and difference may inform the concept and application of *independence* so that it is relevant and important for older persons with disabilities.

The earlier successes of *independence* within the disability rights movement beg the questions: Could *independence* be used within home care if it is conceptualized as a choice and framed from a rights-perspective? How would *independence* look under these conditions? Answering these questions draws in questions of rights and human need. The use of *independence* as a right requires a base of commitment to support and the consideration of dependence and need as acceptable. In the current context, dependence is perceived as negative, illegitimate, undesirable. Use of *independence* conceptualized from a rights based perspective would require viewing dependence as acceptable. In this sense, Pat Armstrong's (2001) concept of the "Right to Care" and Len Doyal and Ian Gough's (1991) articulation of "Universal Human Needs" are helpful as starting points.[21] *Independence* would look very different if care were considered as either a basic human right or a basic human need. Both of these concepts represent a shift toward integrating both humanistic notions into care as well as the all-inclusive or universal. As such, health framed as a universal human right or need within homecare would alter the conditions under which dependent persons are perceived and responded to. Such a commitment to human notions of care and rights may lessen the dichotomy between dependence as the state to be avoided and *independence* as the ultimate aim. In this sense, *independence* may be conceptualized as relevant for older persons with disabilities.

Following this, *independence* would look very different if care/support were considered/provided as an entitlement. As an example, consider the Nordic Welfare State where the choice of service provision places humanistic ideals at the forefront. Although the placement of human need before economic need is admirable, considering that this choice of humanistic rights means a sacrifice in global competitiveness (Gough, 2000), it is most unlikely that the current context will shift to this choice of welfare state. Yet, human need and care as entitlement are useful concepts to inform priorities about care, which have and continue to shift to a decisional framework of managed risk. As ill-health has an economic cost, choices informed by human need, rights, and the commitment to care may actually benefit the current system through preventative investments (Gough, 2000). This choice to consider a human needs framework based on rights, and work within the current limits is only a step toward greater flexibility in care. The intention is to begin exploring ways that to move away from the stigma associated with dependence/independence to a conceptualization that is useful for older persons with disabilities receiving care.

In addition to human needs as universal values in homecare, flexibility must be incorporated within this universal concept so that it does not continue to exclude persons based on social location or essentialize diversity or difference within experiences. Herein lies the integration of 'thick' needs which attempts to understand the naming of needs in specific cultural contexts (Drover & Kerans, 1993).[22] As such, *independence* may be an acceptable term if the diversity and different ways of achieving *independence* are recognized and taken into account in relation to service. Acceptable conditions would mean that *independence* be considered a western modern value that may not have the same meaning for all persons (e.g., Aboriginal, Asian communities, etc.).

This flexible interpretation of need could include both the necessity of meeting basic human needs as well as recognizing the importance of the 'how' or the 'process' of having these needs met. In this sense, the focus on the differences in how *independence* is conceptualized and negotiated is important. Subsequently, *independence* may be interpreted differently depending on social location, culture and identity. For one person or group, *independence* may mean choice, while for another it may mean connection with one's family, or maintaining an image of oneself as strong despite decline. As such, a flexible notion of need may open possibilities to take account of differences within human need and contribute to a broader conceptualization of *independence* in homecare which is relevant and useful.

Move toward a broader conceptualization of *independence,* which incorporates diversity and difference in home care, may be a relevant and useful concept for older persons with disabilities. In this sense, I suggest that a more flexible interpretation be adopted in homecare. This interpretation would be informed by a social or human model of care, which both considers care as a human needs or right, and accounts for different understandings and experiences of *independence* according to social location and within-group differences. In terms of application within homecare, I would make an important distinction between promoting *independence* as a value or ideal (i.e., choice of how services would be provided), and achieving *independence* as goal or outcome (i.e., avoiding dependence/myth of control). Take for example the disability-rights argument, *independence* is not about doing everything for yourself, but about having control over help is provided (Morris, 1997, p. 56; Oliver, 1989). In this sense, *independence* promotes the flexibility for a definition that is inclusive and way of articulating that is helpful as opposed to stigmatizing.[23] *Independence* within a human model would allow for viewing the body as a site of resistance, where identity, need, and service delivery could be negotiated. New conceptualizations such as this could assist older persons with disabilities to negotiate or resist dependency and live within their bodies as opposed to fragmented from them (i.e., embodied selves). It is from this negotiated or contested position that we may view not only the similarities amongst groups of older persons and persons with disabilities, but respect differences within.

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Amanda M. Grenier, Ph.D., recently completed her dissertation on "Diverse Older Women: Narratives Negotiating Frailty" and is currently a postdoctoral fellow at the Centre on Social Gerontology at Keele University (UK). Her current research looks at managed care. In January 2004, she will take up a position as Assistant Professor at the McGill School of Social Work.

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1. This article has limited the discussion of independence to the context of public homecare services. As such, it neglects at least two central ideas. One is a discussion of the real differences that exist between the target group of this article (i.e., group labeled "dependent" in relation to homecare policy eligibility) and healthy older persons who are not currently in need of service and/or may purchase these services through the private market. The distinction of the ability to purchase services is an important factor in the equation as persons outside and inside the public system are most likely viewed in different ways. As such, it applies only to the group of older persons considered "dependent" and the impacts that language choice within policy may have on both the provision of services, as well as individuals and groups who receive services. It does not intend to paint a powerless portrait of aging and/or disability but to question the ways in which policy may organize experience. The second idea that is neglected within this work is the recognition of various forms of strength and/or resistance within individuals and groups of older persons and persons with disabilities.
2. The term demographic transition is a term that refers to the increasing numbers of older persons, implying that an increase in the number of older persons will have a significant impact on the service sector. Demographic transition is often paired with demographic crisis. For a discussion on this topic see Gee and Gutman (2000) "The Overselling of Population Aging: Apocalyptic Demography, Intergenerational Challenges, and Social Policy."
3. Here, persons considered dependent refers to those groups eligible under targeted social policy efforts. This includes older persons, persons with physical disabilities, cognitive impairment or intellectual disabilities as well as mental health issues.
4. Terminology used will correspond with policy transitions; the use of older persons and persons with disabilities separately reflects periods of time where these two groups were considered separate target groups, while the use of older persons with disabilities reflects the current eligibility for home care policy in Quebec which includes persons with disabilities regardless of age. This article however, does not explore issues or implications of grouping older persons and persons with disabilities, which are beyond the scope of this paper. For a discussion regarding the definition and politics of recognition as "Disabled" see Wendell (1996) Chapter One: Who is Disabled.
5. For a discussion of independence in relation to mental health see Goodwin (1997)

"Independence, Risk and Cumpulsion: Conflicts in Mental Health Policy."

6. Community care refers to the policy framework for care. This notion represented a shift from institutional care to care provided in the community. The idea of community care was that the 'sick' person lives at home and receives support from their family, friends, and neighbours (i.e., community). At times, community care (i.e., policy concept) and homecare (i.e., system of service delivery) are used interchangeably.
7. Parish-based services were the main service providers in Quebec. As such, the response to dependent persons in Quebec has specificity, which is beyond the scope of this paper. The role of church involvement adds another level of discourse and means that the transitions in response to dependent persons were experienced slightly different in Quebec. Notably, Quebec's involvement in formal response to dependent persons came later, but led the way in community-based services. For a discussion of the emergence of social services in Quebec see Mayer 1988.
8. Within this discourse and debate on cost and burden, early notions of deservedness were questioned; older persons privileged status gained through labour contributions shifted to status of non-productive and therefore undeserving.
9. The examples below include only the specific meanings relevant to understand independence in the context of health and long-term care. I have excluded the specifications that were repetitive of the general definition (i.e., not dependent), focused on ecclesiastical polity, linear independence (i.e., axioms), politics (i.e., independent labour party), media (independent broadcasting), and mathematical.
10. For a discussion of the development of dependence see Fraser's "A Genealogy of 'Dependency': Tracing a Keyword of the U.S. Welfare State." For dependence in relation to older persons see Walker's "Dependency and Old Age."
11. Quebec home care policy is selected as an example of how independence is applied within practice—not for it's specificity or differentiation from home care policies within other Canadian provinces, the United States or Britain.
12. By nature, eligibility criteria distinguishes between those considered needy or most at-risk and those who do not meet the required guidelines for services. As a result, at the same time as eligibility criteria permits access for some it is restricting access for others.
13. This is particularly the case for high-risk clients who are recognized within a specific profile. As a result of their profile, these clients are eligible to receive special services or increased access in comparison to the regular population. Within Quebec home care, clients assigned the "guichet unique" profile are recognized for being at high-risk for institutionalization and therefore are eligible for targeted services within home care. This profile however, is managed differently according to regional health centres (CLSCs).
14. "Evaluation of Autonomy: MultiClientele" for the Region of Montreal-Centre includes sections on State of Health, Living Habits, Activities of Daily Living, Mobility, Communication, Mental Functions, Activities of Domestic Life, Psychosocial Situation, Economic Conditions, Physical Environment.
15. Criteria to determine and rank the priority for service (i.e., 1– 4) include the urgency of need, the degree of support from family and friends, and socio-economic level

(Quebec, 1994, p. 20). Examples given within the urgency criteria include psychosocial crisis and hospitalization, while support and socio-economic need are determined by clinical judgement and service allocation committees.

16. Here, there is a major contradiction between the intent of the program reflected by its title and the reality of what needs the program is able to meet under the current conditions. The program title indicates that it is about maintenance and support, perhaps remnants of the earlier rights-based notions of care, while in the current context, lower level, or maintenance needs are not included within the priority system. This difference between intent and reality seems to expose a service gap which exists for older persons with lower level needs to receive home care support. This raises questions regarding the options available for these clients.
17. Please note that these divisions are false, the use as value, eligibility and outcome are overlapping and not as falsely separated as in this text.
18. Note that the current context of productivity only recognizes persons who have made labour contributions as productive. In this sense, productivity is also a gendered concept, which has implications for women who have made unrecognized contributions (i.e., caring) as opposed to involvement with paid labour.
19. See Magnus Reindal (1999) for a discussion of the models of personal autonomy.
20. Here social location refers both to diversity along the lines of ability, age, ethnicity, "race," sexual orientation, socio-economic status, as well as differences within the category of disability which would result in different experiences and needs.
21. Here I am referring to the overall concept of Universal Human Need within Doyal and Gough's (1991) "A Theory of Human Need," not necessarily the basic need satisfiers or minimum level of living.
22. For a debate on "Thick" and "Thin" Theories of need see Doyal and Gough (1991) who suggest a "thin theory of need" (i.e., best level of need satisfaction), and Drover and Kerans (1993) who suggest a "thick theory of need."
23. This articulation would require additional attention when cognitive or decision-making abilities are considered, as well as exploration to determine those who may be excluded by this change.

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