

**UNIVERSITY OF WISCONSIN-MILWAUKEE
HELEN BADER SCHOOL OF SOCIAL WELFARE**

SocWrk 945 - FAMILY AND LONG-TERM CARE ACROSS THE LIFE COURSE

Semester:	Fall 2008	
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COURSE DESCRIPTION: This course uses the life course perspective to examine the family role in the provision of long term care within the context of kinship care, and care of persons with chronic illnesses, developmental and adult disabilities. At the micro level the course will examine the effects of family structures, cultural beliefs, and family histories on the manner in which care is provided and the impact of caregiving on family members and family dynamics. The development and assessment of intervention strategies to support family caregivers will also be critically examined. At the macro level, the course will examine public policies, institutions, and service programs that affect family caregiving. Special attention will be given to differential impacts of socioeconomic factors. Through assigned readings and class discussion, students will learn the demographic and social factors that have made long-term care an imminent social problem. Students will be encouraged to critically examine social values and public policies that have been invoked to address the problem in the US and internationally. Readings from international literature on long-term care will also allow discussion of comparative cultural attitudes, policies, and interventions. Possible programmatic and societal solutions to the challenge of long term care will be examined with attention given to the differential consequences of public policies and social programs for different segments of society.

Prerequisites

Social work doctoral-student status or permission of instructor.

LEARNING OUTCOMES: By the end of this course, students will be able to:

Apply the life course perspective to current and future issues of family caregiving across the life course.

1. Analyze the historical and current role of government in public policies relating to dependency and family caregiving across the life course, including demographic and social factors that have made long-term care an increasingly urgent social problem.
2. Identify the impact of caregiving on family caregivers, care recipients and the family systems.
3. Demonstrate knowledge of federal, state, and local public policies that affect family caregivers across the life course.
4. Identify the social values underlying public policies and the differential impact of policies on different segments of the population, including health disparities related to race, gender and class.
5. Use knowledge of established research methods to critically evaluate studies supporting micro and macro interventions and best practices for supporting family caregivers across the life course.

Student Expectations: It is expected that all readings assignments will be completed prior to the class that they are listed for discussion on the syllabus. *Students should also be prepared for in-depth class discussions and complete any study activities or study questions that have been assigned to guide preparation.*

Required Readings

Caro, F. G. (2007). *Family and Aging Policy*. New York: Haworth Press.

Haber, C., & Gratton, B. (1994). The families of old. In H. J. Graff (Ed.), *Old age and the search for security: An American social history (pp 20-47)*. Bloomington and Indianapolis: Indiana University Press.

Olson, L. K. (2003). *The Not-So-Golden Years: Caregiving, the Frail Elderly, and the Long Term Care Establishment*. New York: Rowman & Little field Publishers, Inc.

Source Books: Large sections of the following books will be used for the class and students may choose to purchase these books or obtain them through library reserve.

Hooyman, N. R., & Gonyea, J. (1995). *Feminist Perspectives on Family care: Policies for Gender Justice*. Thousand Oaks: Sage Publications, Inc.

Lefly, H. (1996). *Family caregiving in mental illness*. Thousand. Oaks, CA: Sage Publications.

Liu, W., & Kendig, H. (2000). *Who should care for the elderly: An east-west value divide*. London: Singapore University Press.

Students must read one of the following books:

Albom, M. (1997). *Tuesdays with Morrie*. New York: Doubleday.

Lustbader, W. (1991). *Counting on Kindness: The Dilemmas of Dependence (2nd Ed.)* New York: The Free Press.

McGowin, D. (1993). *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's Disease*. San Francisco: Elder Books.

These books are designed to provide students with a better understanding of the reciprocal nature of dependence and caregiving from the perspective of care-receivers. The work selected by each student should be read prior to session 8 in preparation for class discussions on dependency.

Learning Environment and Resources

Many course materials are accessible online to registered students through D2L at <http://www.uwm.edu/UWM/Student/elearning.html>. In addition, all students have access to the Schools of Enderis computer lab located on the 10th floor of Enderis Hall and to computer labs located throughout campus (see <https://www3.uwm.edu/IMT/services/campus/ccls/> for specific locations and hours). Campus policies regarding participation by students with disabilities, accommodations for religious observances, academic conduct/misconduct, incomplete grading policies, complaint procedures, grade appeal procedures, sexual harassment and safety policies, final exam date requirements, and other matters are available at: <http://www.uwm.edu/Dept/SecU/SyllabusLinks.pdf>.

Grades will be determined as follows:

Seminar participation	20%
Short paper on caregiver interventions or public policy	20%
Presentation of paper and facilitation of class discussion	15%
Presentation of key arguments for formal class debate	10%
Final paper articulating and defending specific recommendations for long term care in the future	35%

Overview of Graded Assignments

1. **Seminar participation** – Students are expected to participate in analytical discussions of issues and assigned reading materials. Class participation will be determined by students’ active participation in class discussions that reflect thoughtful application of the reading assignments to class exercises and in-class discussion. With the exception of the first class, attendance at 13 of the remaining 15 class sessions and active class participation as defined above will result in full class participation points for class attendance and participation.
2. **Short paper (8 to 10 pages)**– Students will prepare and present a short analytical paper on either:
 - a) an intervention process or program developed to support family caregivers or
 - b) a public program (US or International) intended to support family caregiversThe paper should fully describe the intervention or program and identify strengths and weaknesses.
3. Each student will present their paper and facilitate an analytical discussion among classmates on the issue for a class session on caregiver interventions (sessions 11 or 12) or public policies sessions 13 or 14) .
4. **Presentation of key arguments for formal class debate** – Each student will contribute to the development of an affirmative or negative case on the debate resolution: Each student will participate in the formal debate as a presenter of the initial case or as a presenter of a rebuttal (see appendix).
5. **Final paper** – see appendix

Guidelines for Re-marking Assignments and Exams:

1. If there are individual concerns regarding grading, the entire assignment or exam will be remarked to ensure fairness.
2. Grades could either increase or decrease depending on remarking.
3. Re-marking can only be requested one week after grades are posted.
4. Students must submit a detailed explanation (1 page) of why their assignment warrants a reexamination.

Late Submissions: Late assignments and/or exams will be “down graded” by 5% per 24 hours past due date/time. Assignments more than one week late will not be accepted without prior approval for emergency situations. Missing exams without prior approval or notification of emergency situations will result in an automatic zero.

Class Schedule & Readings

Session	Topic/Readings
1	<p>Demographics of long-term care</p> <ol style="list-style-type: none"> 1. Kinship Care (Grandparent Caregivers) 2. Disabilities 3. Aging <p>Older Americans Update 2006 Fuller-Thomson, E., & Minkler, M. (2000). African American grandparents raising grandchildren: a national profile of demographic and health characteristics. <i>Health and Social Work, 25</i> (2): 109-118. Houtenville, A. J. (2006). <i>2005 Disability Status Reports: United States</i>. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Ithaca, NY: Cornell University.</p>
2	<p>Historical look at family care</p> <p>Haber & Gratton (1994) – Chapter 1 Hooyman & Gonyea (Chapter 5)</p>
3	<p>The state’s role in longer term care: Alternative views of state, family and individual responsibility</p> <p>Liu & Kendig (2000) – Chapters 1-4 Olson (2003) – Chapters 1-2</p>
4	<p>Life course perspective</p> <p>Settersten, R. (2003). Invitation to the Life Course: Toward New Understandings of Later life. Baywood Publishers. – Chapters 1-2 Elder, G. H., & Johnson, M. K. (2003). The life course and aging: Challenges, lessons, and new directions. In R. A. H. Settersten (ed.), <i>Invitation to the life course: Toward new understandings of later life</i> (pp. 46-85). Amityville, NY: Baywood Publishing, Inc.</p>
5	<p>Feminist view of care and caring</p> <p>Hooyman & Gonyea - Chapters 1-4 Moen, P., Robison, J., & Fields, V. (2000). Women’s work and caregiving roles: A life course approach. In E. P. Stoller & R. C. Gibson (Eds.), <i>Worlds of Difference: Inequality in the Aging Experience</i> (pp. 165-175). Thousand Oaks: Pine Forge Press.</p>
6	<p>Patterns of Family Care</p> <ol style="list-style-type: none"> 1. Who, what, why and when? 2. Is there equity in family care? Issues of gender and culture <p>Olson (2003) – Chapters 3, 6 Montgomery & Rowe (2007) Goodman, C., & Silverstein, M. (2005). Latina grandmothers raising grandchildren: Acculturation and psychological well-being. <i>International Journal of Aging & Human Development, 60</i>(4), 305-316. Minkler, M. (1999). Intergenerational households headed by grandparents: Contexts, realities, and implications for policy. <i>Journal of Aging Studies, 13</i>(2), 199-218. McCallion, P., Janicki, M., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent carers II: Service needs and service provision issues. <i>Journal of Gerontological Social Work, 33</i>, 57-84.</p>

7	<p>Costs of Family Care</p> <ol style="list-style-type: none"> 1. Caregiver burden and stress 2. Work and family <p>Parish, S.L., Seltzer, M.M., Greenberg, J.S., Floyd, F.J. (2004). Economic implications of caregiving at midlife: Comparing parents of children with developmental disabilities to other parents. <i>Mental Retardation</i> 42, 413-426.</p> <p>Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y., Hong, J. (2001). Life course impacts of parenting a child with a disability. <i>American Journal on Mental Retardation</i>, 106), 265-286.</p> <p>Minkler, M., & Fuller-Thomson, E. (1999). The health of grandparents raising grandchildren: Results of a national study. <i>American Journal of Public Health</i>, 89(9), 1384-1389.</p>
8	<p>Costs of Dependency</p> <ol style="list-style-type: none"> 1. Experience of dependency 2. Quality of care 3. Elder abuse and neglect <p>Olson (2003) – Chapter 5</p> <p>Baltes, M. M. (1996). What is dependency. In M. M. Baltes, <i>The many faces of dependency</i> (pp.1-24). New York:Cambridge University Press.</p> <p>Each student selects one of the following:</p> <p>Ledbaster: Counting on Kindness Albom: Tuesdays with Morrie McGowin: Living in the Labrynth</p>
9	<p>Alternative Care Settings</p> <ol style="list-style-type: none"> 1. Group homes 2. Nursing home care 3. Assisted living and continuing care communities 4. Quality care issues <p>Buhler-Wilerson (year) – Chapters 1-3</p> <p>Haber & Gratton (year) – Chapter 4</p> <p>Krauss, M., Seltzer, M., & Jacobson, H. (2005) Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. <i>Journal of Intellectual Disability Research</i>, 49(2), 111-124.</p> <p>Magaña, S., & Smith, M.J. (2006). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards co-residence status. <i>American Journal of Orthopsychiatry</i>, 76, 346-357.</p> <p>Olson (2003) - Chapter 7</p> <p>Gottlieb, A.G. & Silverstein, N. M (2000). GrandFamilies house: An innovative approach to addressing needs of custodial grandparents. <i>The Public Policy and Aging Report</i>, 11, 17-20.</p> <p>Levin, C. A., & Kane, R. A. (2007). Resident and family perspectives in assisted living. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.173-192). New York: Haworth Press, Inc.</p>
10	<p>International Perspective</p> <p>Laporte, A., Croxford, R., Coyte P. (2007). Can a publicly funded home care system successfully allocate service based on perceived need rather than socioeconomic</p>

	<p>status? A Canadian experience. <i>Health Social Care in the Community</i>, 15(2): 108-119.</p> <p>Johansson, L., & Sundstrom, G. (2007). Policies and practices in support of family caregivers – Filial obligations redefined in Sweden. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.7-26). New York: Haworth Press, Inc.</p> <p>Stuart, M., & Boll Hansen, E. (2007). Danish home care policy and the family: Implications for the United States. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.27-42). New York: Haworth Press, Inc.</p> <p>Mehta, K. K. (2007). A critical review of Singapore’s policies aimed at supporting families caring for older members. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.43-58). New York: Haworth Press, Inc.</p>
11	<p>Interventions for Family Caregivers I – Linking Research to Practice Student facilitated seminar focused on intervention research.</p> <p>Belle, S. H., Czaja, S. J., Schulz, R., Zhang, S., Burgio, L., Gitlin, L., Jones, R., Mendelsohn, A. B., & Ory, M. (2003). Using a new taxonomy to combine the uncombinable: Integrating results across diverse caregiving interventions. <i>Psychology and Aging</i>. 18(3), 396-405.</p> <p>Czaja S. J., Schulz R., Lee C. C., & Belle S. H. (2003). A Methodology for Describing and Decomposing Complex Psycho-Social Interventions. <i>Psychology and Aging</i>, 18(3), 385-395.</p> <p>Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. <i>Gerontologist</i>. 42(3):356-7.</p> <p>Montgomery, R.J.V., & Kosloski, K. (2006). Pathways to a Caregiver Identity for Older Adults. In R.C. Talley, R.J. V. Montgomery (Eds.), <i>Caregiving Across the Life Span</i>. University of Wisconsin-Milwaukee.: Oxford University Press</p> <p>Hooyman & Gonyea (Chapters 11-15)</p>
12	<p>Interventions for Family Caregivers II: Linking Research to Practice Student facilitated seminar focused on intervention research.</p> <p>Montgomery, R. J. V., & Rowe, J. M. (2007). Respite. In C. Cox (Ed.), <i>Handbook of Social Work Practice and Dementia</i> (pp. 341-362). New York: Springer.</p> <p>Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (in press). Family Caregiving. In C. N. Dulmus & J. A. Blackburn (Eds.), <i>Handbook of Gerontology: Evidence-Based Approaches to Theory, Practice, and Policy</i>. Indianapolis: John Wiley & Sons.</p> <p>Gitlin, L. N., Burgio, L., Czaja, S., Mahoney, D., Gallagher-Thompson, D., Burns, R., Hauck, W. W., Belle, S. H., Schulz, R., & Ory, M. G. (2003). Effect of multi-component interventions on caregiver burden and depression: The REACH multi-site initiative at six months follow-up. <i>Psychology and Aging</i>. 18(3), 361-374.</p> <p>Mittelman, M. S., Roth, D. L., Clay, O. J., Haley, W. E. (2007). Preserving Health of Alzheimer Caregivers: Impact of a Spouse Caregiver Intervention. <i>American Journal of Geriatric Psychiatry</i>, 15, 780-789.</p>
13	<p>US Public Policies and Programs (Federal) Student facilitated seminar focused on federal policies.</p> <ol style="list-style-type: none"> 1. Social Security: Medicare and Medicaid 2. Home and Community Based Services <p>Friedland, R. (2001). Medicaid. In G. L. Maddox (Ed.). <i>The Encyclopedia of Aging</i>. New York: Springer.</p> <p>Meyer, M. H., & Bellas, M. L. (2001). U.S. Old-Age policy and the family. In A. J.</p>

	<p>Walker, Manoogian-O-Dell, L. A., McGraw & D. L. G. White (Eds.), <i>Family in Later Life</i> (pp. 191-201). Thousand Oaks, CA: Pine Forge Press.</p> <p>Gaugler, J. E., & Teaster, P. (2007). The family caregiving career: Implications for community-based long-term care practice and policy. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.141-154). New York: Haworth Press, Inc.</p>
14	<p>US Public Policies and Programs (Federal)</p> <p>Student facilitated seminar focused on federal policies. Older American's Act</p> <ol style="list-style-type: none"> 1. National Family Caregiver Support Program 2. Family & Medical Leave Act 3. Disability Policy 4. Welfare reform <p>Takamura, J. (1999). National health line. Getting ready for the 21st century: The aging of America and the Older Americans Act. <i>Health & Social Work, 24</i>(3), 232-238.</p> <p>Feinberg, L. F., & Newman, S. L. (2007). Preliminary experiences of the states in implementing the National Family Caregiver Support Program: A 50-state study. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp. 95-114). New York: Haworth Press, Inc.</p> <p>Wisensale (2007). Commentary: What role of the Family and Medical Leave Act in long-term care policy? In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp.79-94). New York: Haworth Press, Inc.</p> <p>Turnbull III, H. R., Stowe, M. J., Agosta, J., Turnbull, A. P., Schrandt, M. S., Muller, J. F. (2007). Federal family and disability policy: Special relevance for developmental disabilities. <i>Mental Retardation and Developmental Disabilities Research Reviews, 13</i>(2), 114-120.</p> <p>Anderson, S. (2006). The Impact of State TANF Policy Decisions on Kinship Care Providers. <i>Child Welfare Journal, 85</i>(4), 715-736.</p> <p>Henderson, T., & Cook, J. (2005). Grandma's Hands: Black Grandmothers Speak About Their Experiences Rearing Grandchildren on TANF. <i>International Journal of Aging & Human Development, 61</i>(1), 1-19.</p> <p>Copen (2007). Welfare reform: Challenges for grandparents raising grandchildren. In F. G. Caro (Ed.), <i>Family and Aging Policy</i> (pp. 193-210). New York: Haworth Press, Inc.</p> <p>Hooyman & Gonyea (1995) - Chapter 10</p>
15	<p>Formal debate on proposed change in social policy to impact family role in long term care. (Each student will participate as a member of the “affirmative “ or the “Negative” team)</p>

APPENDIX

Formal Debate

Due date:

Length: see time allotted for each perspective below

Where: in class

Learning Outcomes: 1, 2, 3, 4, 5, 6

Each student will contribute to the development of an affirmative or negative case on the debate resolution: Each student will participate in the formal debate as a presenter of the initial case or as a presenter of a rebuttal.

Format for Formal Debate

Debate Topic:

The U.S. Federal Government should initiate an integrated Long Term Care policy that does not hold family members responsible for Long Term Care in any explicit or implicit way.

Debate Format

- 6 to 8 minute formal presentation of Case including key element of long term care plan.
- Two rounds of 5 minute rebuttals.
- Ten minute break between formal presentation and first rebuttal.
- Five minute break between first and second round of rebuttals.

Final Paper

Due date:

Length: 4500-5500 words, excluding references (must include word count)

Where: Due on D2L at 6:00 p.m.

Learning Outcomes: 1, 2, 3, 4, 5, 6

Your task is to design a policy or program(s) that will improve long term care for older adults in our society. To do this, you may borrow ideas from other countries, build upon or expand current demonstration programs or simply advance your own ideas.

As you design this policy or program be certain to address the following issues:

- (1) Describe the policy/ program in some detail noting major components including when and how it would be implemented.
- (2) Identify key limitations of current long term care system that the proposed policy or program would address.
- (3) Identify the key role that family members would play in the long term care system. Be sure to define who you mean by “family members”.
- (4) Discuss the merits and limitations of the program/policy with regard to
 - Affordability of the program to individuals and society
 - Equity of the program for different segments of society
 - Choice that the program/policy would give to individuals and families.
- (5) Discuss the barriers that would need to be overcome to implement your program or policy.
- (6) Summarize the primary costs and benefits of the policy/program.

Be sure to use original data sources to support your ideas and statements.

All sources must be cited using American Psychological Association (APA) format. Please refer to the handout on D2L or access the following link for more information on properly citing sources:

[http://www.wisc.edu/writing/Handbook/American Psychological Association \(APA\) Documentation_M.pdf](http://www.wisc.edu/writing/Handbook/American_Psychological_Association_(APA)_Documentation_M.pdf)