Multiple Dimensions Of Caregiving and Disability

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Defining Dimensions

Bulk of knowledge base concerns caregiving in age-related scenarios

Other scenarios
• Children with disabilities, SHCNs
• Acquired disabilities traumatic, chronic
• Aging parents of adults IDDs
• Grandparents as caregivers
• Children in caregiving roles
Consequences and Implications

Incomplete picture of family caregivers  *numbers lacking*

Lack of a coherent model of caregiving across scenarios

Separate silos of clinical service

Lack of comprehensive, informed policy
Similarities and Commonalities Across Scenarios

CGs are *de facto* extenders of care
Policymakers view CG as a family obligation, *women will be there to supplement care as needed*

Costs to society are immense

Cuts to services for CGs presented as “cost-saving” measures
*Medicaid, home-based services*
Rates of Disability are Increasing

Increasing number of people with chronic health conditions

Improved emergent care, longer life expectancy “epidemic of survival”

Some conditions require ongoing assistance that may necessitate a life-long commitment from a family member
Costs to Society Escalate with Returning Veterans

in Elliott and Parker chapter

Signature wound: traumatic brain injury polytrauma, PTSD

TBI is a chronic disease process

cognitive deficits, neuroendocrine changes, pain, risk of mental health problems, CTE and dementia

TBI and PTSD have increased risk of aggression, interpersonal abuse
Emerging Opportunities

Affordable Care Act (2010) resources, supports, facilitators

Increased attention from agencies, professional organizations

http://www.caregiver.va.gov/

http://www.dvbic.org/family-caregiver-curriculum

Who are the “people with disabilities”? 

Traditionally defined by medical diagnostic conditions

Increase in the number of chronic health conditions and accompanying co-morbidities, secondary complications

Affects the “count” - one out of five, one out of four  Crews chapter
ICF Model of Disability

from Crews chapter,
Holms & Raina chapter
## ICF Model of Disability

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<th>Body Functions &amp; Structures</th>
<th>Activities &amp; Participation</th>
<th>Environmental Factors</th>
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<td><strong>Functions</strong></td>
<td><strong>Capacity</strong></td>
<td><strong>Barriers</strong></td>
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<td><strong>Structures</strong></td>
<td><strong>Performance</strong></td>
<td><strong>Facilitators</strong></td>
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The ICF Model Informs Caregiver Policy

Appreciating caregiver needs on individualized basis limitations, activities in the home, community

Understanding risk factors

Appreciating variability in adjustment, feelings over time positive growth, resilience; depressed, distressed

-Getch chapter

from Kuhlthau chapter
Strategic Training and Support

Recognize CGs as “…experts on the realities of their daily lives”

Strategic use of doctoral-level providers

*McDaniel & Pisani chapter*

Strategic and culturally-sensitive training and education

*Goldsmith chapter, Leung chapter*

Use of home-based interventions

*Elliott & Parker chapter*
Legal and Life Planning Issues

Navigating confusing, contradictory policies, eligibility legal cases e.g., Alberto N http://pcaf.tamu.edu/

Keep caregivers informed of legal issues and implications Bowe chapter

Long-term care and life planning Viola & Arno chapter
A Model for Developing and Sustaining a Comprehensive Care Plan (CP)

Requirements:
Achieving CP goals requires the sustained, cooperative efforts of the care recipient, family caregivers, other significant caregivers, and a number of trusted professional advisors.

Necessary steps include:
* Understanding of the landscape of caregiving tasks (e.g., medical > locating a medical specialist) associated with a particular condition.
* Completion of initial assessment with health, legal, financial, and spiritual advisors.
* Initiation and completion of all required tasks using state of science and practice resources.
* Identification of high priority tasks
* Ongoing reassessment and task completion as conditions change
Summary

Need for informed, comprehensive policies for caregivers

Refine the science base to provide policy-relevant research

Develop contemporary, cost-efficient programs to support caregivers over time and as needed