



UIC UNIVERSITY OF ILLINOIS AT CHICAGO

**DISABILITY AND
HUMAN
DEVELOPMENT
COLLEGE OF
APPLIED HEALTH
SCIENCES**



RESEARCH ON FAMILY CAREGIVING SUPPORT IN THE UNITED STATES: A STRATEGIC PLAN

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Agenda/ overview

- Family Support Research and Training Center (FSRTC)
- Strategic Plan Process
 - *List of Topics*
 - *Conceptual Frameworks*
- Exploration & Discovery
- Services & Interventions
- Policy
- Need to Diversify Research Methods

Family Support Research and Training Center ([FSRTC](#))

- Aim: To develop and disseminate family support research and training to inform more cohesive policies and practices related to family support.
 - *Define the state of science in family support.*
 - *Generate new knowledge in the critical policy areas of self-direction and managed care and in culturally competent peer-to-peer family interventions.*
 - *Generate and implement a vision for policy and practice in family support through a national resource center.*
- University of Illinois at Chicago (Institute for Disability and Human Development)
- Funded by National Institute of Disability, Independent Living, & Rehabilitation Research (NIDILRR)

Process

- Family Support-Need to Know campaign
 - *Online, pen-and-paper, call-in line*
- Literature Reviews on Family Support
 - *Special Issue – Volume 19, Issue 4*
- Expert Panel Survey
- Expert Panel Meeting
- State of the Science in Family Support
 - *Preliminary list of topics for strategic plan*



List of Topics

Exploration & Discovery



- Family caregivers in communities of color
- Persons with disabilities
- Range of family caregiver types/contexts
- Range of disability/impairment contexts
- Healthcare access and systems navigation
- Positive caregiving outcomes
- Family caregiver economic/employment experiences

Services & Interventions



- Barriers to access and service utilization
- Impact of attitudes, structure, and system complexity
- Supports for the whole family
- Best practices
- Development and adaptation of services and interventions for families of color

Policies



- Consumer-directed home and community-based services
- Disability employment policies
- Family Medical Leave Act
- National Family Caregiver Support Program
- No Wrong Door policies
- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act
- Respite services

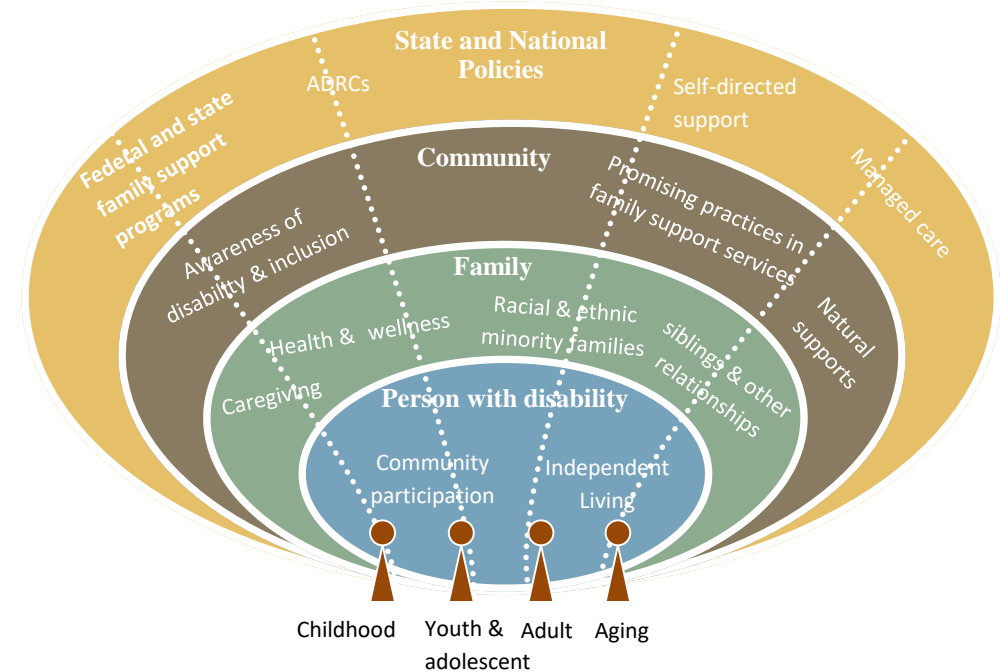
Research Methods



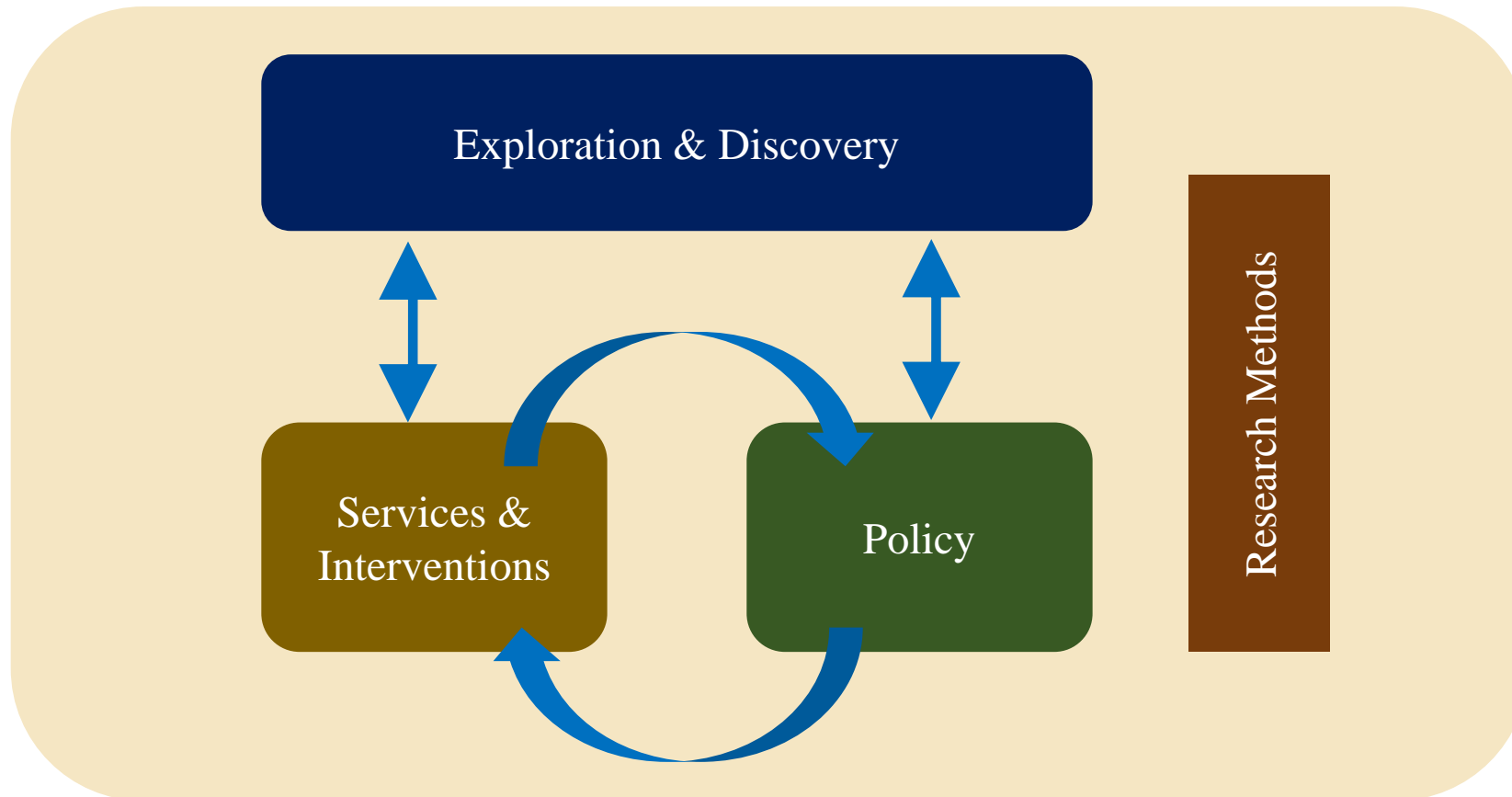
- Cost benefit analyses/social benefit of family caregiving
- Longitudinal studies
- Qualitative research
- Secondary analysis of national data

Frameworks for developing the strategic plan

- NIDILRR's Stages of Research Model
 - 1) *Exploration and Discovery*
 - 2) *Intervention Development*
 - 3) *Intervention Efficacy*
 - 4) *Scale up evaluation*
- Life course theory
 - *Individuals and families change over time, as people age*
- Ecosocial model (Bronfenbrenner, 1979)



Frameworks for developing the strategic plan



A vertical image on the left side of the slide shows a chalkboard with a lightbulb and some chalk markings.

I. Exploration and discovery

01

In Communities of Color

02

For Persons with Disabilities

03

For Different Family Members

04

Across Multiple Disability Types

05

Across Multiple Social Contexts

06

With Health Care Access and Systems Navigation

07

With Positive Caregiving Outcomes

08

With Economic and Employment Outcomes

Experiences of family caregivers in communities of color

- Research has been inconsistent
- Some groups regularly overlooked
 - *Asian Americans, Native Americans, Arab Americans*
- Steps to more adequately and accurately capture the experiences of family caregivers in communities of color:
 - *Oversample underrepresented racial and ethnic groups, immigrants and refugees.*
 - *Compare family caregiver experiences across race/ethnicity and culture.*
 - *Examine within group factors among specific racial and ethnic groups.*
 - *Examine cultural issues such as cultural values, and practices including religion and spirituality that should be considered in services and intervention development.*



Future Directions in Exploration & Discovery:

Design studies that adequately include caregivers across racial and ethnic populations. Oversampling underrepresented groups, examining outcomes and factors within underrepresented groups and comparing outcomes and factors across groups, are ways to accomplish this. Within this overarching priority, researchers should consider studies that:

- Include persons with disabilities as part of the family being studied. Studies should consider including questions and outcomes related to the family member with disabilities in addition to caregiver outcomes
- Broaden the research populations beyond maternal caregivers and spouses (e.g., include fathers, siblings, grandparents, and other family members)
- Study experiences of caregivers of persons with disabilities not represented in the literature, and conduct comparisons of caregiver outcomes across disabilities
- Examine family caregivers' experiences with accessing and navigating different service systems
- Include positive outcomes and variables in caregiver studies
- Examine the impact of caregiving on caregiver employment and economic outcomes



II. Services & Interventions

01

Piloting Interventions

02

Promoting Elements of Best Practices

03

Building the Evidence Base

Examples

■ Future is Now

- *Developed for families of individuals with IDD*
- *Efficacy research consisting of experimental design (Heller & Caldwell, 2006)*
- *Next step (effectiveness): translation across populations*

■ Parent Taking Action

- *Developed for Latino mothers of children with ASD*
- *Efficacy research consisting of experimental design (Magaña, Lopez, & Machalicek, 2015)*
- *Next step (effectiveness): cultural adaptation across different communities.*



Future Directions in Services & Interventions:

Increase efforts to develop, adapt, and tailor services and interventions for culturally diverse persons with disabilities and their family caregivers. Within this overarching priority, researchers should consider studies that:

- Develop new interventions to address unmet needs of family caregivers, especially for populations that experience unique linguistic, cultural, and economics barriers
- Utilize study designs and approaches to generate initial evidence of effectiveness for pilot studies
- Examine existing recommendations of best practices (e.g., use of technology, family-focused service provision, cultural tailoring, and training to address provider attitudes and beliefs) and explore how services and programs can be exported to new populations or scaled up to larger populations
- Integrate existing evidence-based practices into the evaluation of promising practices



III. Policy

01

Consumer Direction in Home and Community-Based Services

02

Disability Employment Policies

03

Family Medical Leave Act

04

National Family Caregiver Support Program

05

No Wrong Door

06

Recognize, Assist, Include, Support, and Engage Family Caregiver Act

07

Respite

Examples of Policy Research

■ Disability Employment Services

- *Studying caregivers over time and across states to see how state policy changes affect caregiver employment*
- *Examining how people with disabilities transitioning out of sheltered workshops into other forms of employment relates to caregiver employment*

■ No Wrong Door systems

- *How are these systems alignment efforts coordinating with other caregiver services?*
- *How are these systems reaching out to underserved populations (people of color, LGBTQ people, caregivers other than spouses)?*



Future Directions in Policies:

Determine utility, effectiveness and cost-benefit of the policies that affect family support of people with disabilities (e.g., consumer directed services, the Federal Medical Family Leave Act, National Family Support Program, No Wrong Door, the RAISE Act, respite, and disability employment programs).

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- Examine integration of systems of information and referral across disability types, caregiver types, and the life course
- Study how changes in policy affect outcomes for caregivers and people with disabilities in the short and long-term



IV. Need to Diversify Research Methods

01

Cost-Benefit Analysis and Cost-Effectiveness Research

02

Longitudinal Studies

03

Qualitative Research

04

Secondary Analysis of National Data

Diversifying Methods in Family Support Research

- Cost-benefit analysis/cost-effectiveness research
 - *What are the long-term impacts of family caregiver support programs and policies on caregiver wellbeing and family finances, and society?*
- Longitudinal studies
 - *How do changes in health policy relate to changes in outcomes for caregivers and people with disabilities?*
- Qualitative research
 - *Data collection by bicultural, bilingual researchers to gather information of family caregiving in communities of color*
 - *How do men (fathers, grandfathers, husbands/partners) experience caregiving?*
- Secondary Analysis of National Data
 - *How can we generate more information on caregivers in regularly collected surveys? For example, adding a caregiver question to the Behavioral Risk Factor Surveillance Survey (BRFSS)*



Future Directions in Research Methods:

Design studies that address the changing experiences of disability, family, and family caregiving over time. Research needs to connect caregiving to a variety of health, financial, and family functioning outcomes, and document the unique needs and experiences of underserved communities. Future research designs should:

- Connect the impact of family support services/programs/policies to larger societal goals (e.g., employment, health expenditures)
- Follow up with participants over time to address the impact of individual, familial, and macro/social changes on outcomes
- Provide opportunities for underserved populations to participate, identify their unmet needs, and tell their stories
- Expand the capacity of existing datasets to inform the knowledge base on family caregiving

Next Steps

- Finish the strategic plan document (October 2018)
 - *Two rounds of feedback, highlighting priorities within each topic and section*
- Distribute the document to stakeholders
 - *Family caregivers, organizations, researchers, government/funders*
- Apply strategic plan to next set of research projects

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Thank You Questions?



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