

# Independent Choices: Family Caregivers and Adults with Disabilities in Arkansas

by J. K. Eckert, P. San Antonio, K.  
Siegel, L. Simon-Rusinowitz, K. J.  
Mahoney

UMBC and the University of  
Maryland, College Park

**Presented at the Gerontological Society of America's 54th  
Annual Scientific Meeting, Chicago IL, November 17, 2001**

# Purpose of Study

- To provide detailed stories of consumers' experiences with the cash option
- To address four questions
  - How program made a difference in lives of participants?
  - How participation in program compares with previous arrangements?
  - How are services provided?
  - How does the program work?

# Focus on 27 Care Units composed of :

- Consumer/representatives (27)
- Paid workers (27)
- Counselors (5)

# Methods

- Purposive sample based on selected demographic characteristics deemed important in Arkansas (age, race, sex, amount of monthly cash benefit, type of care worker)
- Semi-structured, open-ended, face-to-face interviews with each unit member

# Sample

	<u>Number</u>
• Age	
– 16-64	11
– 65+	15
• Sex	
– Male	12
– Female	14
• Race	
– Black	15
– White	12
• Care Worker	
– Family	19
– Non-Family	7
• Representative	
– Yes	8
– No	18

# Interview protocols

- Focus on topical areas:
  - Background
  - Services
  - Operation of program
- Questions developed with input from Cash and Counseling Management Team

# Analysis

- Transcribed interviews were uploaded into qualitative analysis software (NUD\*IST)
- Software facilitates:
  - Management of large textual data base
  - Coding and thematic analysis
  - Searching for patterns of coding
  - Creation of integrated stories

# The Stories

- Twenty-seven care unit stories were developed
- Stories included multiple perspectives (consumer/representative, PCW, counselor) on:
  - Personal meaning of program participation
  - Managing the provision of care
  - Experiences with care prior to participating in the program

# Cross-Cutting Themes

- The family context of care
- The meaning of Independence
- The community context of care
- Skills and qualities of caregivers
- Value of the IndependentChoices Program
- Alternate uses of the cash benefit
- Experiences with agency workers

# Focus on the family context of care

- Family helps anyway
- Family pitches in
- Importance of the family relationship in paid caregiving
- How program helps family

# Family helps anyway

- Program participation formalized a pattern of caregiving that, in many cases, started years earlier
- Family members were caring for consumer prior to enrollment in the program

# Family pitches in

- Often the paid family worker relied on other family members to pitch in and help them
- Family members confer on care, finances and provide physical help

# Importance of the family relationship in paid caregiving

- Family members do more for a consumer than a paid non-family caregiver
- Family members know and understand consumers' needs because of shared experiences and histories
  - Less embarrassing for family to provide personal services
  - Greater sense of trust and safety
  - Greater affection in relationship
  - More independence

# Program helps families

- Program participation provides:
  - Employment opportunities
  - Respite care
  - Educational opportunities
  - Reduces worry, e.g., stealing, being left alone

# The value of the IndependentChoices Program

- Widely shared themes among participants
- Value included:
  - Flexibility and freedom
  - Control and responsibility
  - Getting out more
  - Securing services from someone who cares about you
  - Securing help that fit the rhythms of life
  - Choice in whom you hire
  - Being able to choose a family member