Voices of Families: The Critical Role of Aging Parents and Siblings
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Part One

After 40 Years, Where Do We Go From Here?

Aging Caregivers in the Heartland

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“You can be very close to it, but if you’re not walking in the shoes, you just don’t know it.”
Indiana Family Support Research Project

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Need for the Study

• 15,253 with caregivers age 60+
• Retain family-supported living arrangements
• Prevent crisis situations
• Explore potential supports
Qualitative Research Overview

(1) Interviews: aging parents & siblings
(2) Provider agency focus groups
(3) Self-advocates focus group
Aging Caregiver Interviews

- Questionnaire
- Recruitment
- Interviews
- Data analysis
The Caregivers and their Households...

- 21 Family Interviews
- Age range 50-88
- Racial/minority representation
- Gender/Marital Status
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Characteristics continued...

- Educational status
- Community Tenure
- Waiver status
- Caregiving careers
- Mobility/independence of adult sons and daughters
Perceptions of Physical & Mental Health Status

Would you say that in general your health is...

- Excellent
- Very Good
- Good
- Fair
- Poor
- Very Poor

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How many days during the past 30 days

...was your physical health not good?
“What do you mean by Not Good?

There hasn’t been a day in the last 30 days that I haven’t gotten up and done my job. There have been days when I’ve been so stiff that it might be 3 or 4 o’clock in the afternoon when the stiffness goes away, but there’s nothing I can do about it.”
How many days during the past 30 days

...did poor physical health keep you from doing your usual activities?
How many days during the past 30 days...was your mental health not good?

“Thirty. [laughter] That’s an exaggeration, but it’s always on your mind.”
Daily Routines

What is a typical day for you?
“Then I fall into my recliner and say my prayers: ‘Here I go.’ By the time I get her up and out of the house I’m exhausted.”
Families’ Perceptions of the Service System

Are there any particular frustrations or problems that you have with services?
“The constant change, the constant fear, ‘is this going to be approved?’

You’re really held hostage, so that every year at review time for her Waiver it’s just panic time.”
“Why can’t **we** make the decisions on what we need? We best know our daughter.

They’ve never cared for a person with a disability, but they’re telling us we don’t need this, and we don’t need that...”
“We found out she would have access to all kinds of **funds that she doesn’t get by living with us.** If she lived alone or in a [group] home, the government would bring all these funds in for her.”
Respite Services

“I don’t feel comfortable with it because I don’t know the type of people that they hire.”
Perceptions about Caregiving

Do you ever feel you don't have enough time or opportunity to do things just you want to do?
“There are times when I simply can’t get away. I haven’t had a vacation in 10 years.”
“My sisters say ‘You just don’t have any time of your own,’ well, I don’t have, because I know he comes first.”
“It’s very involved for us. I can’t die, you know?” [Laughter]
Reciprocity

“He’s brought a lot of joy to a lot of people. What irritates me worse than anything is when somebody says, ‘How do you deal with him?’”
“She’s just so intertwined in my life that [when she goes away to camp] I don’t know how to function without thinking of her.”
Social Support Networks

“It’s difficult to find people that understand.”

“It would be great to know what other people are going through.”
Planning for the Future

In the event that you are no longer able to care for your son/daughter, who will become their caregiver?
“It’s not a real easy thing for [my wife] and me to sit down and talk about.”
“It bothers me not to know what’s going to happen to him. I know the kids would take care of him. But how and where?”
“My son has got to be known by everyone in the community. That’s my protection when I’m dead. They’ve got to know, they’ve got to care.”
After 40 years...

Families still need a responsive family service system.
Families consistently said the service system should include:

- Simplicity and consistency
- Access to needed services
- Family-directed care and
- Adequate funding
And those became the overarching themes.
What do families mean by “simplicity and consistency”?
What do families mean by “access to needed services”? 

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What do families mean by “family-directed care”?
What do families mean by “funding, adequate funding?”
Dimensions of Family Functioning...

The strength and fragility of the household ebbed and flowed, depending on the day, the current needs, supports available, etc.
The Wheel of Family Functioning

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A text equivalent to this graphic is posted online at:
http://www.iidc.indiana.edu/index.php?pageId=3484
Five Policy Recommendations were developed from these themes, along with the perspectives of the family caregivers, individuals with disabilities and service providers.
Recommendation 1

Assess the family system as well as the individual with a disability...
Recommendation 2

Expand and clarify the definition of ‘respite’...
Recommendation 3

Expand support for planning for the future...
Recommendation 4

Promote access to existing information resources...
Recommendation 5

Support for education and training for family caregivers and individuals with disabilities...
Looking to the future...
Thank you.

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