

Family support and intergenerational caregiving: Report from the State of the Science in Aging with Developmental Disabilities Conference

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Abstract

Background: This article summarizes the proceedings of the Family Support and Intergenerational Caregiving work group that was part of the “State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Living” symposium.

Objectives: The aim was to provide a research and policy agenda that would result in a better social, health, and economic well being for adults with intellectual and developmental disabilities and family caregivers.

Methods: Key issues addressed were (1) demographic challenges; (2) long-term outcomes, poverty and cultural minority status; (3) interdependent roles of family members; and (4) family support policies and practices.

Results: The group identified the following major gaps in knowledge that need to be included in a future research agenda: data on the demography of families, including information on cultural minorities and families living in poverty; research on the interdependent roles of various family members in providing support to each other, including siblings, grandparents, and the person with disabilities; and development and assessment of models for providing supports to families and that bridge the aging and disability networks.

Conclusion: The outcomes of this recommended research agenda will result in progressive policies and culturally sensitive supports that will improve the health, social, and economic well-being of adults with IDD and their families. © 2008 Elsevier Inc. All rights reserved.

Keywords: Aging; Intellectual and developmental disabilities

Introduction

Families are the main care providers for individuals with intellectual and developmental disabilities (IDD) with over 75% of these adults reported to be living with their families [1,2]. Over 25% of these care providers are over the age of

60 years [3]. These families tend to receive few formal family support services and face long waiting lists for residential services, with over 73,828 families estimated to be waiting for residential services [4]. Furthermore, many families have not made plans for residential transitions [5,6]. Hence, most adults with IDD are likely to continue remaining in their family home, yet little research has addressed the health and well-being of these families. Also, family support policies have lagged behind the need.

This paper presents the results of the Family Support and Intergenerational Caregiving Work Group that was part of the “State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Living” symposium. The families and intergenerational work group focused on the health and social needs of aging caregivers, particularly those living in poverty who are from minority cultural backgrounds. This included examining ways to assess unmet service needs, improve access to services, and increase sensitivity to cultural and linguistic competence. The long-term outcomes were to provide a research and policy agenda that would result in better social, health, and economic well-being for adults with IDD and family caregivers. In the

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§ A list of participants is given at the end of the article.

shorter term, the symposium addressed the following questions with the aim of increasing our understanding of the process and outcomes of family caregiving and of promoting changes in policies and practices supporting families:

1. What are the demographic challenges affecting family caregiving for adults with I/DD?
2. How does poverty and cultural minority status affect the health, social, and economic status of families of adults with I/DD?
3. What are the interdependent roles of family members, including parents, siblings, grandparents, and adults with I/DD?
4. How can we best support families in providing care in and out of the family home, including ways to bridge the aging and disability networks to advance progressive policies?

Symposium Process

The Family Support and Intergenerational Caregiving work group was part of the “State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Living” symposium, held on May 21 – 22, 2007, in Atlanta, GA. The entire symposium lasted 2 days and included keynote presentations by key experts (identified by the track leaders and facilitators) in the field for each of the tracks. The keynote for the Family Support and Intergenerational Caregiving Work Group was Marsha Seltzer, who was chosen as a leading researcher on family caregiving across the life span for people with I/DD. Her talk summarized key research, discussed gaps in the literature, and suggested future recommendations with the intention of stimulating further discussion. This was followed by presentations on specific topics and discussions of the family support work group for a series of four sessions across the 2 days. The work group was led by Tamar Heller and facilitated by Alan Factor with notes being taken by two graduate students.

Each of the first three sessions had a specific theme that began with an expert or experts presenting major research findings and posing discussion items. The topics and presenters included the following: (1) Demographic Challenges and Health Outcomes, Glenn Fujiura and Sandra Magana; (2) Reciprocal Caregiving Roles and Support, Tamar Heller and Alan Factor (who presented material sent by Lynn Feinberg); and (3) Family Support Policies and Practices, Michelle Putnam and Joe Caldwell. Work group participants included 10 key researchers on family issues, 5 family members and people with I/DD; 3 graduate students, and 4 leading service providers from both the disability and aging communities. The fourth work group break-out session was devoted to synthesis of the research findings and gaps and development of consensus on a list of recommendations. After the first draft of this paper was developed, it

was sent to all the participants for feedback and comments and revised accordingly.

The Study Group Discourse

Demographic challenges

Knowledge of family demography is central to the development of informed disability policy. In addition to the “graying of America,” the trends in the United States over the past 50 years of more dual-income families, lower fertility rates, and more families living in poverty have increased the demands on families in general [7,8]. These demands are often greater for parents of adults with I/DD, who face longer periods of caregiving extending into their old age, when their own caregiving capacity decreases.

Other important trends include the increased number of minority families and families living in poverty, which now comprise nearly 13% of U.S. families. The percentage of non-Hispanic Caucasians is estimated to drop from 69% in 2004 to 50% of the population in 2050 [9]. Cultural caregiving norms and language barriers reflecting our increasingly diverse society are creating a hidden need for services that typically do not surface until families are in a crisis situation. Poverty and lack of health insurance also affect the health and well-being of family members and their ability to provide support.

Fujiura [10] noted the additional important trends of labor shortage and increased immigration. These trends have significant implications for the pool of direct support professionals who will need to help provide support in caring for adults aging with I/DD. Shortages in this labor market will impose constraints on the independence and integration of persons with disabilities. Direct support professionals receive low pay and have excessive rates of turnover, affecting the quality of care. A crisis is looming as the “Baby Boomer” generation reaches old age. One solution to the labor shortages could be the increased immigration pool. Since 1990, 70% of population growth has been through immigration. Further research needs to examine the impact of these population changes on the pool of available direct support professionals and the quality of care provided.

A trend that has negatively affected our ability to expand our knowledge of the demography of families with a member having I/DD is the tendency to use functional/activity limitations rather than diagnostic illness/impairment-based definitions of disability in national data sets, such as the Survey of Income and Program Participation and the National Health Interview Survey. Fujiura [10] pointed out that this change has made it difficult to measure the needs of these families as distinct from the needs of other families. It is important that we continue to research the demography of families of adults with I/DD as these numbers are critical to developing informed public policies that take into account changing family structures, cultural issues, and families’ financial resources.

Long-term outcomes, poverty, and minority status

While most families adapt well to having a family member with I/DD, families can be at risk for poorer health, social, and economic outcomes. Drawing on two large population-based samples, the Midlife Development in the US (MIDUS) and the Wisconsin Longitudinal Study, Seltzer et al. [11] noted that while mothers show increased negative affect after receiving their child's diagnosis of an I/DD, over time families adapt well to having a child with I/DD. Yet there is the social impact on mothers of having fewer visits with friends. In addition, there is an economic impact on families including lower maternal rates of employment and lower family savings and more family-work role strain [11]. These findings point to both the gendered aspects and the financial cost of care for individuals with I/DD that need to be further investigated.

Families of individuals with developmental disabilities often experience even higher rates of poverty than other families [2]. In addition, they spend considerable out-of-pocket costs for the care of their relative with disabilities [12,13]. For example, the lifetime cost of care for a person with autism is an estimated \$3.2 million [14]. Among families, disability and poverty intersect as disability results in greater poverty, and in turn, poorer families often experience more disability.

Little data, however, exist on the relative economic impact of severity of the disability, the time demands of caring for the child with disabilities, or the differential impact on minority families, who comprise a greater share of American families. Often, these minority families have less access to disability services than do other families [15].

Magana and Smith [16] noted that their analysis of data from the National Health Interview Survey found a more negative impact of caring for an adult with I/DD among minority families. In one of the first studies that compared caregiving in this population within a minority group, they found that African American and Latino caregivers of adults with I/DD were more likely to report having arthritis than were their noncaregiving counterparts and the Latino caregivers were more likely to report depression [16]. They stressed the importance of studying health behaviors and access of these families.

Discussions centered on the need to examine the cultural and gendered aspects of caregiving, including the economic impact on families. While the gerontological research and policy agenda is now beginning to address the public health risks of caregiving for elderly family members, the health risks for parents or other family caregivers of adults with I/DD has mostly been ignored in both research and policy initiatives. Furthermore, we need to incorporate not only convenience samples of volunteers who may have more favorable outcomes than other families but also samples that are more representative of the general population, including minority families. We also need to develop and study culturally competent interventions targeted to caregivers' well-being along with the well-being of the adult with I/DD.

Interdependent roles: parents, grandparents, siblings and the adult with I/DD

Although they play important roles in the lives of adults with I/DD, few studies focus on their fathers, siblings, or grandparents. The predominant focus has been on mothers, who are usually the primary caregivers. We know little about what happens when these mothers can no longer be the main providers of care. In some cases, fathers are able to take on more tasks. As both parents age or die, siblings usually assume more responsibility, ranging from service oversight and advocacy to primary care. Yet, as Heller and Kramer [17] point out, parents often exclude them from family discussions of future plans for their siblings with disabilities. They also noted that the siblings who are more likely to take over caregiving responsibility include those who live nearby, who are the same gender, and who are already more involved with their sibling with disabilities [17]. Discussions from the group emphasized the need to examine issues faced in distant caregiving as many siblings live far away from their brothers and sisters and of spouses of siblings who also play significant roles in providing support both to their spouses and to the family member with I/DD. We know even less about the perspectives of adults with disabilities toward their siblings.

Few studies have examined the role of adults with I/DD in providing support to other family members. Most family research is based on the assumption that caregiving is unidirectional, that is the provision of care by family members to the person with I/DD. Yet, in many cases the person with disability provides support to other family members, particularly elderly parents who have growing support needs as they age. Family support fiscal policies have not kept pace with this phenomenon. We need to study the nature of this support and ways to help adults with I/DD overcome barriers in fulfilling these roles.

Family support policies and practices: bridging aging and disabilities

Despite the fact that most adults with developmental disabilities live with families, only about 5% of developmental disabilities funding is designated for family support [18]. U.S. disability policy tends to be more focused on individuals rather than on families. Given the demographic imperative of the growing aging population and the increasing demands for long-term services, policymakers need to consider policies that support families and avoid costly institutional placements. A report from a National Consensus Development Conference [19] stressed the importance of viewing families as "consumers" in addition to as "providers." Feinberg [21] noted that the use of comprehensive family assessments with concomitant supports could reduce the risk of institutionalization and Medicaid and Medicare costs. Establishing caregivers' assessment as a component of practice across settings—with the goal of strengthening

families—calls for a fundamental change of thinking in policy and practice.

Caldwell [12] noted that continued efforts are needed to expand flexible, consumer-directed supports, which have been shown to increase family well-being, improve family access to health care, increase self-determination of adults with I/DD, and decrease institutional placements. Putnam [20] added that we need to know more about preferences of families and of what policies work best for which families. Research on families caring for persons with Alzheimer's disease has indicated that some families prefer to have someone else navigate the system, while other families prefer consumer direction.

Research is needed that looks at the health and social needs of aging caregivers, with special attention to the needs of minority caregivers and those living in poverty. The efficacy and effectiveness of various policies and practices will need to examine not only family well-being but also the cost-effectiveness of approaches. One area that has been woefully neglected has been the perspective of people with disabilities regarding their families and the nature of support they desire.

A broad public policy agenda is needed that would include both developing supports within the developmental disabilities service system and forging coalitions with other aging and disability groups to advance legislation for family caregivers. Key examples of federal legislation and programs that incorporate both the aging and disability networks include the Lifespan Respite Act, the National Family Caregiver Support Program, and the Aging and Disability Resource Centers. We need further research to examine the extent that these programs are serving adults with I/DD and their families and the effectiveness of these programs in addressing the needs of this population.

General Conclusions and Recommendations

Families will continue to provide the bulk of care for adults with I/DD. It is important to look at these families as a unit of focus, including examining the outcomes of providing lifelong care. As parents experience their own age-related frailties, there will be a greater demand for direct support professionals who can provide home-based care. At the same time, the pool of these workers is shrinking.

Although much of the focus on families has centered on parents, siblings are assuming a larger role in providing support to the family member with I/DD as parents age and can no longer provide care. Yet siblings are often unprepared for this responsibility. People with I/DD are not only recipients of care but may also assume some caregiving responsibility for their parents in later life.

Family support policies and funding have lagged behind the increased demand for family support services. Models of providing support include consumer-directed services, psychoeducational training, and future planning

interventions. These models have the potential to bolster families' caregiving capacities. Many of the initiatives stemming from the aging network and bridging to the disability network, such as the Aging and Disability Resource Centers and the National Family Caregiving Support Program also hold promise for addressing the needs of these older caregivers.

Drawing on the presentations and the discussions within the break-out sessions, the Family and Intergenerational Caregiving Work Group developed recommendations in the following areas:

Demography and long-term outcomes

- Assess how the changing family structure and public policies affect families caring for an adult with I/DD, including the health and financial impact on families.
- Determine the differential impact of providing long-term care for an adult with I/DD on women versus men, minorities, and those with lower income.

Roles and interdependence

- Determine how patterns change after parental retirement and death, including the roles of siblings, spouses of siblings, distant caregivers, and the adult with I/DD.
- Develop and study models to better support grandparent caregivers.
- Study the role that adults with I/DD play in caring for parents and methods for supporting them in that role.

Policies and practices

- Develop models for comprehensively assessing family needs and using these assessments to improve the health of family caregivers.
- Identify the best models for providing family supports (including consumer-directed support, psychoeducational training, and respite programs), and assess their cost-effectiveness.
- Promote collaboration across aging and also other interest groups (e.g., autism).
- Assess the extent to which the Aging and Disability Resource Centers are serving the needs of people with I/DD and their families.

Participants

Sandra Magaña, Ph.D., University of Wisconsin; Glenn Fujiura, Ph.D., University of Illinois at Chicago; Michelle Putnam, Ph.D., Washington University; Alan Factor, Ph.D., University of Illinois at Chicago; John Kramer, M.A., University of Illinois at Chicago; Nora Handler, R.R.T.C.A.D.D.; Ray Murphy, R.R.T.C.A.D.D.; Marie Murphy, R.R.T.C.A.D.D.; Susan Parish, Ph.D., University of North Carolina; Nina Zuna, M.Ed., University of Kansas; Zolinda Stoneman, Ph.D., University of Georgia; Ann

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