The American Occupational Therapy Association
Report to the Executive Board

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TO: AOTA Board of Directors

SUBJECT: Request for Board Action

TOPIC: Ad Hoc Workgroup on Families and Caregivers Across the Lifespan

Executive Summary

This summary addresses the process and outcomes of our efforts to "identify occupational therapy issues related to care giving and to consider if we, as a profession, are missing the mark relative to our potential for contribution"(letter from Carolyn Baum: July 7, 2005).

The title of this report is intended to clarify the nature of the population that is the focus of our concern. Caregiving is an anticipated feature of parenting for families with very young and school-aged children, and may extend to adult children as well. Families frequently serve in a caregiving capacity with their extended family members (parents, siblings, grandparents, etc.). The role of caregiver may be filled by non-family members who provide this service as paid employees (the formal support system), or on a voluntary basis (the informal support system). Caregiving may be provided at home, in community settings, in acute care or residential facilities. The complexities of this practice domain require explication of the contexts in which families and caregivers perform their caregiving roles and an understanding of the unique demands associated with various life-cycle stages. Thus, this report is directed towards families and caregivers (both informal and formal) across the lifespan.

The collective expertise and knowledge of our members is reflected in all aspects of the following report. Each individual has advanced practice experience among diverse client populations, including gerontology, mental health, early intervention, developmental disabilities, cognitive and physical disabilities, and represent a broad cross-section of the United States, including the Northeast, Midwest, Mid Atlantic, and New England states.

The success of this "long distance" effort bears testimony to the collegiality of the individuals involved, their commitment to the task at hand, and their ability to use the available technology to gather information, communicate, to review, share, and edit their work. From the beginning, each member took responsibility for completing a specific assignment relative to the overall work scope. Questions and issues were identified and discussed and progress was reported on a regular basis vis-à-vis five scheduled telephone conferences that included all members of the group. Agendas were prepared and followed for each phone conference and the outcomes/minutes were distributed via email to all the members.

Action Items and Relation to Strategic Plan:

The following action items and goals are not listed in order of priority. Rather, they are organized and presented sequentially to provide a cohesive planning framework. The objectives for each goal presented below appear in **TABLE 1** (see attached), along with specific mention of their correlation with the goals and objectives of **AOTA'S Strategic Plan.**

ACTION ITEMS

1. **GATHER DATA**

   Goal: Recognize Families and Caregivers Across the Lifespan as an essential and increasingly significant domain of occupational therapy practice.

   Goal: Support research to explore the efficacy and cost-effectiveness of OT intervention with families and caregivers at each life-cycle stage.

2. **PACKAGE MATERIALS**

   Goal: Develop a Family and Caregiver Toolkit that emphasizes occupational therapy's role with families and caregivers. Materials must reflect cultural sensitivity.

   Goal: Develop a public relations campaign and ensure that all materials reflect cultural sensitivity and are relevant to the cultures for whom they are intended.

3. **DISSEMINATE DATA**

   Goal: Develop continuing education opportunities which incorporate the evidence gathered and that emphasize occupational therapy's role with families and caregivers.

   Goal: Develop targeted marketing and advertising campaign to include advocacy.

   Goal: Advocate for legislation and policies that support provision of services to families and caregivers with disabilities and chronic illness, across the lifespan.

4. **EVALUATE OUTCOMES**

   Goal: Provide fiscal and editorial resources to conduct an analysis of the published outcomes of funded research on the efficacy of occupational therapy practice with families and caregivers of persons with disabilities and chronic illness, across the lifespan.

   Goal: Assess the effects, over time, to establish Families and Caregivers Across the Lifespan as a significant domain of OT practice.

Fiscal Implications

Following consultation with Staff Liaison, Janie Scott, it was determined premature to include fiscal implications at this phase of the process. The major task undertaken thus far was to conduct a preliminary exploration of issues related to families and caregivers across the lifespan. The recommendations that emerge from this report will be forwarded to the AOTA Board of

Directors. The report itself will provide the background materials that the Visioning Group Leaders will consider when they meet early in 2006. If families and caregivers continue to be a priority and recommendations are made to the Representative Assembly, fiscal implications will be determined based on current priorities and recommendations.

Full Report: Families & Caregivers Across the Lifespan

Statement of the Problem

Occupational therapists typically partner with parents, families, and caregivers of individuals with disabilities and chronic illness across the lifespan. That partnership occurs in a variety of treatment settings across all stages of the life-cycle, from early intervention with very young children, to school-based programs for older students, to patient education and discharge planning for adults in healthcare settings, and to working with older adults in their own homes as well as in long-term care settings.

Occupational therapists have made significant contributions to the geriatrics and pediatrics family and caregiving literature (Corcoran & Gitlin, 1992; Crowe, 2002; Dooley & Hinojosa, 2004; Esdaile, 1996; Gitlin, 2003; Gitlin, Corcoran, Winter, Boyce, & Marcus, 1999; Hanft, & Anzalone, 2001; Hasselkus, 1993; VanLeit, & Crowe, 2002).

The occupational therapy literature addresses the challenges of providing family-centered services, and the role of environmental influences on occupational performance for caregivers and care recipients (Clark, Corcoran, & Gitlin, 1995; Gitlin, Corcoran, Leinmillereckhardt, 1995; Humphry, 1995; Lawlor, Mattingly, 1998; Moyers, 1992; Olson, & Esdaile, 2000; SchultzKrohn, 1997; Segal, 2004).

Yet, despite their recognition as key professionals who promote client function, safety, and community living (Horowitz, 2002a, 2002b; Peterson, Howland, Kielhofner, et al.,1999; Walker, & Howland, 1991), occupational therapists often are not identified as the primary professionals in practice settings. Their multiple contributions (which include providing targeted caregiver education; training and skill-building; psychosocial support; reduction of "excess-disability" among care recipients; reduction of caregiver burden; promotion of safety, health, and well-being for both caregivers and care recipients) often go unrecognized and unappreciated.

Background Information

Families who provide informal caregiving (assisting a family member or friend without being paid to do so) present personal, family, economic, and public health issues. Formal (paid) caregiving generally refers to paid assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Care recipients may be of any age, and may receive either or both types of care.

Family Caregiving and Adults

The population of the United States, as well as their associated needs, is changing. In 1900, only 4.1% of Americans lived to age 65. In 2020, that number is predicted to be 20.7% (Administration on Aging, 2005). With advances in treatment, people are surviving medical crises that they could not have lived through in previous years, but they may be living with chronic conditions. Today 125,000,000 Americans (45% of the population) have at least one

chronic condition. The number of people with chronic conditions will reach 157,000,000 by 2020 (Partnership for Solutions, 2005).

In the United States, more than 44 million people provide care for a chronically ill, disabled, or aged family member or friend during any given year (NAC &AARP, 2005). The average length of time spent on caregiving for a family member over the age of 50 is about 8 years (MetLife, 1999). The value of the services that US family caregivers provide for "free" is estimated to be $257,000,000,000 per year, twice what is actually spent on homecare and nursing home services (Arno, 2002). In fact, family caregivers provide the overwhelming majority of homecare services in the US, approximately 80% (US Agency for Healthcare Research and Quality, 2000).

Elderly spousal caregivers with a history of chronic illness themselves, who are experiencing caregiving-related stress, have a 63% higher mortality rate than their non-caregiving peers (Schulz and Beach, 1999). The stress of family caregiving for persons with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends, thus increasing their chances of developing a chronic illness themselves (Glaser and Glaser, 2003). Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses, the rate is six time higher; for those caring for a parent, the rate is twice as high.

Unmet needs of caregivers of older adults (NAC & AARP, 2004) include:

- Finding time for myself (35%)
- Keeping the person I care for safe at home (30%)
- Balancing my work and family responsibilities (29%)
- Managing my emotional and physical stress (29%)
- Easy activities I can do with the person I care for (27%)
- How to talk with doctors (22%)
- Making end-of-life decisions (20%)
- Moving or lifting the person I care for (16%)
- Managing challenging behaviors, such as wandering (14%)
- Choosing an assisted living facility (13%)
- Choosing a home care agency (13%)
- Managing incontinence or toileting problems (11%)

About half of all caregivers assist their loved one with personal care. Yet, less than one in five (18%) say they have received formal training on how to care for this individual (NAC & AARP, 2004). Many of these unmet needs fall within the scope of occupational therapy to resolve, by working with the caregiver, or with the caregiver and care recipient.

Family Caregiving and Children/Young Adults

The 2000 US Census identified more than 5,000,000 people, aged 5 to 20, living with a disability, and an additional 30+ million aged 21 to 64 (US Census Bureau, 2000). As of 1992, 2.2% of children under 3, 5.2% of children 3 to 5, 6.3% of 6 – 14 year olds, and 9.3% of 15 – 17 year olds have conditions that cause limitations in age-appropriate activities (CDC, 1995). In 2002, another survey found 7.1% of children under 18 had activity limitations caused by chronic conditions (CDC, 2005). In the absence of children performing the activities themselves, they are accomplished with the assistance of family or paid caregivers. These limitations include mobility, activities of daily living, and school participation, all within the scope of occupational therapy practice to teach both children and their caregivers the most effective means for task accomplishment.

In working with families of young children with development delays and/or developmental disabilities, occupational therapy services range from evaluation and treatment planning to direct intervention to address deficits in motor skills, language skills, social skills, etc., to working directly with families and with other health care and education professionals in a variety of environments (center based, home based, hospital based, school based). Families often need to play dual roles, acting both as the child's parent and as their therapist/teacher in order to reinforce therapeutic and educational strategies at home. These dual demands often create stressors for the entire family system.

Assuming a client-centered approach expands the role of occupational therapy in providing direct assistance to families to meet their needs dealing with transition issues, future planning and future employment guidance, and consideration of independent living options.

Paid Caregivers

Estimates vary on how many individuals are in the paid caregiving workforce. The Bureau of Labor Statistics (2003), counted approximately 2.4 million workers in the three direct-care categories it tracks: nursing aides, home health aides and personal assistance workers/aides. Other estimates are as high as three million direct care workers (Seavey, 2005). It should be noted that the ability to count caregivers becomes more blurred, as more programs allow payment to family members for care.

The ongoing increase in numbers of older Americans has been well-documented, particularly for people 85 years old and older. Increasing numbers of people are living longer with chronic illnesses and disabilities, which may require complex care and sophisticated technology. In contrast, families are having fewer children, and the pool of available family caregivers is shrinking. With less help available, the stress on those who do provide care may increase, negatively affecting those individuals' physical, financial, and emotional health (Seavey, 2005).

The paid caregiving workforce is also facing challenges. High turnover, difficult work, and low compensation all contribute to difficulties hiring quality staff, and this industry is subject to the same demographic influences as the pool of family caregivers.

Strategies have been proposed to increase and sustain the pool of paid caregivers. One theory is that improving pre-employment training and continuing education reduces turnover by giving workers the competence and confidence they need to do the job well (Paraprofessional Healthcare Institute (PHI), 2005). Training, including hand-on skills, safety (worker and client), infection control, communication, and behavior management, is required by the Federal government for basic credentialing for Certified Nursing Assistants (CNA) and Home Health Aides (HHA). There may be a similar local requirement for Personal Care Assistants (PCA), but these vary by state. Ongoing training, according to Federal law, must address weaknesses and provide specialized knowledge needed to care for a particular client or resident population (PHI, 2005). This may be an opportunity for occupational therapy to contribute to the retention of competent paid caregivers, while improving the quality of care provided to clients.

Direct support professionals, those who work with individuals with developmental or intellectual disabilities, provide assistance with ADLs and other personal care and housekeeping needs. They may also help consumers become better integrated into community life. The Federal government has no training requirements for these individuals, although most states require some training (PHI, 2005). The relationship between needed skills and OT expertise is clear, making OT a potential partner in recruitment, retention, and quality care.

A major concern for both paid and unpaid caregivers is that care is not given at the expense of the provider's health. Understanding not only the therapeutic strategies, but how to provide care in an ergonomically correct manner, can minimize caregiver injury and its secondary effects on the client. Occupational therapists can bring this expertise to the therapeutic situation to benefit both client and caregiver.

Implications for the Profession

- Potential for an increased emphasis in occupational therapy preprofessional and clinical education programs on expanding knowledge, skills, and intervention approaches to more effectively meet the growing needs of families and caregivers.

- Potential for creating a heightened interest in AOTA membership among non-members who work with families and caregivers and might find value in the profession's focusing attention and resources on enhancing occupational therapy's contribution to this practice area.

- Potential for increased advocacy efforts to enhance the limited funding available for family and caregiver programs.

- Potential for increased recognition of the need to address fall prevention and promote caregiver and client safety across the care continuum.

- Potential for increased awareness of occupational therapy's role in prevention and utilization of evidence-based approaches from the ergonomics and fall prevention literature.

- Potential for establishing expanded partnerships with community-based organizations that historically provide education and services to families and caregivers (i.e. Alzheimer's Association).

- Potential for enhanced efforts to institute policy initiatives related to organizational policies and third party reimbursement that address the need to:

  1) Conduct a comprehensive literature review to:

     - Evaluate the ways in which caregiver interventions promote care recipient capabilities, safety and health, reduce caregiver distress and burden.

     - Determine whether these services postpone institutional LTC placement.

     - Evaluate the efficacy of occupational therapy family and caregiver interventions for clients, families and caregivers across the lifespan.

  2) Include wording to recognize families and caregivers as 'clients" in the Definitions section of the American Occupational Therapy Association Standards of Practice.

  3) Provide students, practitioners, clients, caregivers, and families with tools to support increased occupational therapy educational interventions related to community mobility and safe driving.

Recommendations Considered

The recommendations considered were those that seemed consistent with the steps necessary to accomplish the first, and most important goal--the recognition of Families and Caregivers Across the Lifespan as an essential and increasingly significant domain of occupational therapy practice. The achievement of that goal would suggest that the concerns expressed and the information provided in the problem statement and background information provided in this report would, most likely, have been addressed.

Those recommendations, with accompanying goals and objectives, are presented in **TABLE ONE** of the Executive Summary.

Resources Needed

We recommend that any final action taken on these recommendations include adequate monetary resources for research and information dissemination. Additionally, it is encouraged that staff time and contributions are tabulated and included with any recommendations that are adopted**.**

References

Administration on Aging, "Older Population by Age: 1900 to 2050". From www.aoa.gov/prof/Statistics/online_stat_data/AgePop2050.asp, downloaded 9/6/05.

Anderson, G. (2004). Chronic conditions: The cost and prevalence of chronic conditions are increasing. a response is overdue. Expert Voices, 4.

Arno, P. (2002). Economic value of informal care-giving. Paper presented at the American Association of Geriatric Psychiatry. Feb.

Clark, C., Corcoran, M. & Gitlin, L. (1995). An exploratory study of how occupational therapists develop therapeutic relationships with family caregivers. American Journal of Occupational Therapy, 49(7), 587-594.

Corcoran, M., & Gitlin, L. (1992). Dementia management: An occupational-therapy home-based intervention for caregivers. American Journal of Occupational Therapy, 46(9), 801-808.

Dooley, N., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. American Journal of Occupational Therapy, 58 (5), 561-569.

Esdaile, S. (1996). A play-focused intervention involving mothers of preschoolers. American Journal of Occupational Therapy, 50(2), 113-123.

Gitlin, L. (2003). Conducting research on home environments: Lessons learned and new directions. The Gerontologist, 43(5), 628-637.

Gitlin, L., Corcoran, M., Leinmiller-Eckhardt, S. (1995). Understanding the family perspective- An ethnographic framework for providing occupational therapy in the home. American Journal of Occupational Therapy, 49(8), 802-809.

Gitlin, L., Corcoran, M., Winter, L., Boyce, A., Marcus, S. (1999). Predicting participation and adherence to a home environmental intervention among family caregivers of persons with dementia. Family Relations, 48(4), 363-372.

Kiecolt-Glaser, J. K., Preacher, K. J., MacCallum, R. C., Atkinson, C., Malarkey, W. B. & Glaser, R. (2003). Chronic stress and age-related increases in the proinflammatory cytokine IL-6. PNAS, 100(15), 9090-9095.

Hanft, B. & Anzalone, M. (2001). Issues in professional development: Preparing and supporting occupational therapists in early childhood. Infants and Young Children, 13(4), 67-78.

Humphry, R. (1995). Families who live in chronic poverty- Meeting the challenge of family-centered services. American Journal of Occupational Therapy, 49(7), 687-693.

Hasselkus, B. (1993). Death in very old age- A personal journey of caregiving. American Journal of Occupational Therapy, 47(8), 717-723.

Horowitz, B. (2002a). Rehabilitation utilization in New York State: Implications for geriatric rehabilitation in 2015. Topics in Geriatric Rehabilitation, 17, 78-89.

Horowitz, B. (2002b). Occupational therapy home assessments: Supporting community living through client-centered practice. Occupational Therapy in Mental Health, 18, 1-17.

Metlife Mature Market Institute (November 1999). "The Metlife Juggling Act Study: Balancing Care-giving with Work and the Costs Involved." Metropolitan Life Insurance Company, New York, NY.

Moyers, P. (1992). Occupational therapy intervention with the alcoholic's family. American Journal of Occupational Therapy, 46(2), 105-111.

National Alliance for Care-giving and AARP. "Family Care-giving in the US: Findings from a National Survey." June 1997. National Alliance for Care-giving, Bethesda, MD and AARP, Washington DC.

National Family Caregiver Association Caregiver Survey, July 2000. From www.thefamilycaregiver.org/sho/2000_survey.cfm, downloaded 9/6/05.

Olson, J., & Esdaile, S. (2000). Mothering young children with disabilities in a challenging urban environment. American Journal of Occupational Therapy, 54(3), 307-314.

Paraprofessional Healthcare Institute (PHI). (2005). The role of training in improving the recruitment and retention of direct-care workers in long-term care. Workforce Strategies, 3, 1-11.

Peterson, E., Howland, J., Kielhofner, G., Lachman, M.E., Assmann, S., Cote, J., & Jette, A. (1999). Falls self-efficacy and occupational adaptation among elders. Physical and Occupational Therapy in Geriatrics, 16, 1-16.

Schulz, R. & Beach, S.R. (1999). Care-giving as a risk factor for mortality: The care giver health effects study. Journal of the American Medical Association, 282(23), 2215-2219.

Schultz-Krohn, W. (1997). Early intervention: Meeting the unique needs of parent-child interaction. Infants and Young Children, 10(1), 47-60.

Seavey, D. (2005) Family care and paid care: Separate worlds or common ground? Better Jobs Better Care, 54(5), 1-12.

Segal, R. (2004). Family routines and rituals: A context for occupational therapy interventions. American Journal of Occupational Therapy, 58(5), 499-508.

Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes. Research Alert, November 8, 2000. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/news/press/pr2000/ltcpr.htm

US Census Bureau, "Profile of Selected Social Characteristics: 2000. From http://factfinder.census.gov/servlet/QTTable?_bm=y&-geo_id=D&-qr_name=DEC_2000_SF3_U_DP2&-ds_name=D&-_lang=en&-redoLog=false, downloaded 8/31/05.

Van Leit, B., & Crowe, T. (2002). Outcomes of an occupational therapy program for mothers of children with disabilities: Impact on satisfaction with time use and occupational performance. American Journal of Occupational Therapy, 56(4), 402-410.

Walker, J.E. & Howland, J. (1991). Falls and fear of falling among elderly persons living in the community: Occupational therapy interventions. American Journal of Occupational Therapy, 45, 119-122.

Appendix 1

References provided by AOTA search – formed the basis of most citations listed above

1. Author(s): CLARK, CA; CORCORAN, M; GITLIN, LN – gero
   Title: An Exploratory-Study Of How Occupational Therapists Develop Therapeutic Relationships With Family Caregiver
   Source: American Journal Of Occupational Therapy, 49 (7): 587-594 Jul-Aug 1995

2. Author(s): CORCORAN, MA; GITLIN, LN – gero
   Title: Dementia Management - An Occupational-Therapy Home-Based Intervention For Caregivers
   Source: American Journal Of Occupational Therapy, 46 (9): 801-808 Sep 1992

3. Author(s): CROWE, TK – peds
   Title: Consistency Of Family Routines Over Time In Families With Children With Disabilities
   Source: OTJR-Occupation Participation And Health, 22: 92s-93s Suppl. 1 Win 2002

4. Author(s): DECKER, B – peds
   Title: A Comparison Of The Individualized Education Plan And The Individualized Family Service Plan
   Source: American Journal Of Occupational Therapy, 46 (3): 247-252 Mar 1992

5. Author(s): DOOLEY, NR; HINOJOSA, J - gero
   Title: Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention.
   Source: American Journal Of Occupational Therapy, 58 (5): 561-569 Sep-Oct 2004

6. Author(s): ESDAILE, SA – peds
   Title: A play-focused intervention involving mothers of preschoolers
   Source: American Journal Of Occupational Therapy, 50 (2): 113-123 Feb 1996

7. Author(s): GITLIN, LN – gero
   Title: Conducting research on home environments: Lessons learned and new directions
   Source: Gerontologist, 43 (5): 628-637 Oct 2003

8. Author(s): GITLIN, LN; CORCORAN, M; WINTER, L; BOYCE, A; MARCUS, S – gero
   Title: Predicting participation and adherence to a home environmental intervention among family caregivers of persons with dementia
   Source: Family Relations, 48 (4): 363-372 Oct 1999

9. Author(s): GITLIN, LN; CORCORAN, M; LEINMILLERECKHARDT, S – gero
   Title: Understanding The Family Perspective - An Ethnographic Framework For Providing Occupational-Therapy In The Home
   Source: American Journal Of Occupational Therapy, 49 (8): 802-809 Sep 1995

10. Author(s): HANFT, BE; ANZALONE, M – peds
    Title: Issues In Professional Development: Preparing And Supporting Occupational Therapists In Early Childhood
    Source: Infants And Young Children, 13 (4): 67-78 Apr 2001

11. Author(s): HASSELKUS, BR – gero
    Title: Death In Very Old-Age - A Personal Journey Of Care-giving
    Source: American Journal Of Occupational Therapy, 47 (8): 717-723 Aug 1993

12. Author(s): HELITZER, DL; CUNNINGHAM-SABO, LD; VANLEIT, B; CROWE, TK - peds
    Title: Perceived changes in self-image and coping strategies of mothers of children with disabilities
    Source: OTJR-Occupation Participation And Health, 22 (1): 25-33 Win 2002

13. Author(s): HUMPHRY, R – peds
    Title: Families Who Live In Chronic Poverty - Meeting The Challenge Of Family-Centered Services
    Source: American Journal Of Occupational Therapy, 49 (7): 687-693 Jul-Aug 1995

14. Author(s): LAWLOR, MC; MATTINGLY, CF – peds
    Title: The Complexities Embedded In Family-Centered Care
    Source: American Journal Of Occupational Therapy, 52 (4): 259-267 Apr 1998

15. Author(s): MEYERS, C – peds
    Title: Among Children And Their Families - Consideration Of Cultural Influences In Assessment
    Source: American Journal Of Occupational Therapy, 46 (8): 737-744 Aug 1992

16. Author(s): MOYERS, PA – mental health, family dysfunction
    Title: Occupational-Therapy Intervention With The Alcoholics Family
    Source: American Journal Of Occupational Therapy, 46 (2): 105-111 Feb 1992

17. Author(s): OLSON, J; ESDAILE, S – peds
    Title: Mothering young children with disabilities in a challenging urban environment
    Source: American Journal Of Occupational Therapy, 54 (3): 307-314 May-Jun 2000

18. Author(s): PIERCE, D; FRANK, G – peds
    Title: A Mothers Work - 2 Levels Of Feminist Analysis Of Family-Centered Care
    Source: American Journal Of Occupational Therapy, 46 (11): 972-980 Nov 1992

19. Author(s): SCHULTZKROHN, W – peds
    Title: Early intervention: Meeting the unique needs of parent-child interaction
    Source: Infants And Young Children, 10 (1): 47-60 Jul 1997

20. Author(s): SEGAL, R - peds
    Title: Family routines and rituals: A context for occupational therapy interventions
    Source: American Journal Of Occupational Therapy, 58 (5): 499-508 Sep-Oct 2004

21. Author(s): VANLEIT, B; CROWE, TK – peds
    Title: Outcomes of an occupational therapy program for mothers of children with disabilities: Impact on satisfaction with time use and occupational performance
    Source: American Journal Of Occupational Therapy, 56 (4): 402-410 Jul-Aug 2002.

Families and Caregivers Across the Lifespan
Table 1

Recommended Action:	**GATHER DATA**	
Goal	**Objective**	**Corresponding Strategic Plan Goal**
GOAL 1: Recognize Families and Caregivers Across the Lifespan as an essential and increasingly significant domain of occupational therapy practice.	• Develop a roster of experienced and well-informed OT professionals who can provide expert consultation and leadership for this practice area. • Survey clinicians to identify strategies used to address this topic in practice. • Survey educators to identify teaching strategies used to address this topic in professional training programs. • Conduct a literature search to gather information about the nature and diversity of practice perspectives related to working with families and caregivers. • Provide opportunities for and encourage dialogue on this topic at conferences, program directors meetings, and via list-serves. • Identify researchers, educators, and practitioners to collaborate with AOTA to provide support for the development of this practice area.	**AOTA -GOAL III:** TO FOSTER THE DISCOVERY, INTEGRATION, APPLICATION, AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH **C.** Promote high professional standards and continuing competence, and foster success in existing and emerging practice settings. **D**. Foster collaborative relationship among research, education, practice and key Stakeholders and partner organizations.
GOAL 2: Support research to explore the efficacy and cost-effectiveness of OT intervention with families and caregivers at each life-cycle stage.	• Partner with universities and other associations to obtain grants to fund research. • Support evidence-based literature review on the efficacy of OT intervention with families and caregivers, including recidivism and treatment dropouts. • Develop tools for practitioners to use in assessing the needs of families and caregivers. • Collaborate with other professional entities to explore potential uses of technology for providing services and disseminating data.	**AOTA -GOAL III** TO FOSTER THE DISCOVERY, INTEGRATION, APPLICATION, AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH **A.** Advocate for federal and foundation training and research funds and/or opportunities to support the development of scientists and scientific knowledge to advance the profession.

Recommended Action:	**PACKAGE MATERIALS**	
Goal	**Objective**	**Corresponding Strategic Plan Goal**
GOAL 1: Develop a *Family and Caregiver Toolkit* * that emphasizes occupational therapy's role with families and caregivers. Materials must reflect cultural sensitivity. *http://www.aota.org/olderdriver/toolkit.html	• Develop fact sheets about the role of occupational therapy in supporting family and caregivers of people with disabilities and chronic illness, across the lifespan. • Develop materials for legislators to explain the unmet needs of caregivers and families and the potential cost benefit of **supporting** them in their roles at different life-cycle stages. • Develop informational material for payers pertaining to the potential cost benefit of 'covering' occupational therapy for families and caregivers in addition to the identified client. • Collaborate with organizations who have a similar mission to create materials that describe OT's contributions for their constituents.	**AOTA -GOAL III:** TO FOSTER THE DISCOVERY, INTEGRATION, APPLICATION AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH **E.** Disseminate occupational therapy knowledge to a wide variety of audiences
GOAL 2: Develop a public relations campaign and ensure that all materials reflect cultural sensitivity and are relevant to the culture/s for whom they are intended which may require adapted versions for different target populations.		**AOTA- GOAL II:** TO REPRESENT AND ADVOCATE FOR THE ORGANIZATION'S MEMBERS, THE PROFESSION, AND THE NEEDS OF THOSE THE PROFESSION SERVES. **G.** Publicize the profession's positions on regulations and policies that affect participation of all members of society

Recommended Action:	**DISSEMINATE DATA**	
Goal	**Objective**	**Corresponding Strategic Plan Goal**
GOAL 1: Develop continuing education opportunities, which incorporate the evidence, gathered and emphasize occupational therapy's role with families and caregivers.	• Offer conference sessions, printed materials with CEU's attached, and the opportunity to engage in a moderated but informal dialogue about the issues and opportunities in this area to occupational therapy practitioners. • Provide training for practitioners to use the tool kit effectively.	**AOTA -GOAL III:** TO FOSTER THE DISCOVERY INTEGRATION, APPLICATION AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH **C.** Promote high professional standards and continuing competence, and foster success in existing and emerging practice settings.
GOAL 2: Develop targeted marketing/ advertising campaign to include advocacy.	• Distribute printed materials at conferences/ meetings that focus on disabilities and/or chronic illness and provide presenters. • Advocate for early intervention for children and families and coordination of services. • Target all AOTA publications for dissemination of research findings, practice strategies, teaching materials, community programs, etc. that support this domain of practice.	**AOTA- GOAL II:** TO REPRESENT AND ADVOCATE FOR THE ORGANIZATION'S MEMBERS, THE PROFESSION, AND THE NEEDS OF THOSE THE PROFESSION SERVES.
GOAL 3: Advocate for legislation/policies that support the provision of occupational therapy services to families and caregivers of persons with disabilities and chronic illness across the lifespan, and actively oppose legislation/policies that deny them the opportunity to receive these services.		**AOTA -GOAL III:** TO FOSTER THE DISCOVERY INTEGRATION, APPLICATION AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH

Recommended Action:	**EVALUATE OUTCOMES**	
Goal	**Objective**	**Corresponding Strategic Plan Goal**
GOAL 1: Provide fiscal and editorial resources to conduct an analysis of the published outcomes of funded research on the efficacy of occupational therapy practice with families and caregivers of persons with disabilities and chronic illness, across the lifespan.	• Disseminate evaluation outcomes to all stakeholders (e.g. AOTA members; policy makers, advocacy organizations, educators). • Provide workshops and special forums for practitioners, educators, families, and caregivers to share and examine the most/least promising approaches and benefits of occupational therapy intervention for the target population.	**AOTA -GOAL III:** TO FOSTER THE DISCOVERY, INTEGRATION, APPLICATION AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH **A.** Advocate for federal and foundation training and research funds and/or Opportunities to support the development of scientists and scientific knowledge to Advance the profession
GOAL 2: Assess the effects, over time, of efforts to establish Families and Caregivers as a significant domain of OT practice.	• Conduct a focus group among the OT professionals who provided the expert consultation and leadership for establishing this practice area to elicit their perceptions of the process and outcomes. • Conduct a survey among clinicians to identify the strategies they are currently using to address this topic in practice. • Conduct a survey among the educational institutions to identify the current teaching strategies that are used to address this topic in professional training programs. • Conduct a literature search to gather information on the nature and diversity of current practice perspectives related to working with families and caregivers. • Monitor the frequency with which this practice area is included or highlighted at conferences, workshops, and program directors meetings. • Identify the number and nature of collaborative relationships among researchers, educators, and practitioners that have been established to support development of this practice area. • Monitor the amount of and source of funding awarded to support research in this practice area over a five-ten year period. • Produce and disseminate a final report on the overall effect of this effort.	**AOTA -GOAL III:** TO FOSTER THE DISCOVERY, INTEGRATION, APPLICATION AND DISSEMINATION OF OCCUPATIONAL THERAPY KNOWLEDGE TO ADVANCE PRACTICE EDUCATION AND RESEARCH