

## FINDING A FIT BETWEEN WORK AND FAMILY LIFE

### SUPPORT FOR WORKING CAREGIVERS

This issue of *Focal Point* examines the ways in which families with employed caregivers and children with emotional and behavioral disorders manage to meet the demands of employment and family responsibilities. Finding a fit between the demands of work and family life is a struggle for every employed mother and father. For parents whose children have emotional, behavioral, or mental disorders, meeting this challenge can prove extremely stressful, particularly since supportive services are notably lacking. Although Fernandez has estimated that 10% of all employed parents have at least one child with a disability living in their homes, there has been little research on the perceptions of employed parents of children with mental health concerns about the ways in which work and family responsibilities can fit together.

For the past five years, the Research and Training Center for Family Support and Children's Mental Health has conducted a project, Support for Working Caregivers. The researchers studied families with employed caregivers whose children have serious emotional disorders. After examining nearly 400 books and articles, and finding few studies which addressed the balance between work and family, the researchers decided to interview families with children with emotional, mental or behavioral disorders.

Project staff conducted five focus groups of employed parents of children with emotional, behavioral, or mental disorders. These groups explored the perceptions of employed



parents regarding adaptations they made in their work and family life, and the strategies and services they used to achieve a balance between the role of a worker and a parent. This article reports the findings from this study which addressed the strategies and services the parents employed to make these adaptations work in six major domains: employment, child care, education, transportation, financial assistance, and household tasks and management. (See chart, page 4)

The five focus groups were composed of family caregivers who worked more than 30 hours per week and who cared for at least one child with a serious emotional or behavioral disorder. The 41 focus group parents represented a total of 39 families with 106 children, 60 of whom were identified as having serious emotional disorders. Parents were recruited through service provider organizations, parent support groups, family support conferences, and professional contacts. It should be noted that access to services varied widely among focus group members, and was partially dependent on their geo-

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### INCLUSIVE CHILD CARE

For parents to balance work and their children's needs is a challenging task. An additional complication for working parents who have children with emotional or behavioral disorders is to find nurturing, appropriate child care. Some of the barriers to locate suitable child care services involve not receiving equal access to child care settings, the limited number of trained caregivers and the cost of care. A parent advocate, Sherry Archer expressed her concern regarding the accessibility of child care for parents of children with special needs, "Because children with emotional, behavioral or mental disorders are frequently viewed as "bad" or "out-of-control," there may not be the impetus for inclusion of these children in child care settings. Also, empathy for the children or family members may not be present compared to families affected by other types of disabilities."

Additionally, a recent survey by Arthur Emlen of the Regional Research Institute shed light on working parents' perceptions of their child care arrangements. Of the 476 employed parents surveyed, 56 of the parents had a child with an emotional or behavioral disorder that required special attention. Also, he found that of the 56 parents with children with disabilities, 41% responded to the statement, "I've had caregivers who quit or let my child go because of behavioral problems" compared to 2.1% of the 420 parents who reported not having children with disabilities.

In another survey of 2,461 low-income parents receiving child care

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**We invite our audience to submit  
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## SUPPORT FOR WORKING CAREGIVERS CONTINUED

graphic location. Certain states provided more services, and parents who lived in urban areas reported greater access to support than those from rural areas.

Parents reported that they needed to make adjustments in their type and level of **employment**, so that their jobs would be compatible with the demands of caring for a child with a serious emotional disorder. One parent noted, "I would not be looking for a job based upon my capabilities. I would simply look for a flexible, convenient job which would accommodate my hours so that I could only work when my son was in school." Full-time jobs were traded for part-time work, parents switched to employment which had flexible scheduling available, and work aspirations were reduced, with some parents accepting jobs which had fewer demands for time investment and sustained concentration. When faced with the reality that their child's needs dictated their work schedules because of appointments and the child's behavioral problems at school, parents sought out family-friendly employers and occupations.

For some parents, holding paid employment became very difficult, due to the problems they encountered in their attempts to find **child-care**. Since many of the children with serious emotional disorders participated in special education or were mainstreamed into the regular classroom, employed parents were principally concerned with finding child-care before and after school. For most families, child-care centers were not an option due to the children's behavioral difficulties or emotional states. Several parents had enrolled their children in center care, but were soon asked to leave due to their children's behavior problems.

It was not surprising then, that many parents attempted to supervise their children using nuclear family members. In families with two adult caregivers, work schedules were often arranged so that one parent could



provide child-care after school. For single parents, or families with rigid work schedules, child-care was sometimes provided by siblings backed up by parents who responded in emergencies. A single parent remarked, "I have a problem with having my son cared for. Mostly my teenage daughter takes care of him after school and definitely on the weekends. I work every single weekend; sometimes I work seven, eight or nine days before I get a day off. I have to do this in order to support four kids. I can't afford to pay someone to watch a special needs kid. Everyone I sent him to (cares for him), one time only, and they won't do it again. It is too much. It is hard to find people that understand the child's disorder. It is very important that they understand the disorder before they try and take care of a kid with those disorders."

Other parents discussed carrying pagers or cell phones so that they could be contacted in a crisis. Extended family members on a regular basis rarely gave care.

Because of limited options, parents sought child-care assistance from providers willing to come to the child's home. Often hired care providers were not trained to handle children with serious emotional disorders and so parents had to spend time training them. Child-care workers who could nurture children with

emotional disorders were a rare and expensive resource, and they set their own conditions for employment. A parent commented on her child-care conditions and lack of respite time, "Because it was impossible for a one-on-one adult to handle this little girl, we also had a day care provider to take her from after school until 5:00 pm. For an entire year, the only time that I was away from her was when I was at work because the behavior was so bizarre. We could only find one day care person, and the worker said she would absolutely not take her for more than that hour and a half of time." Few families had satisfactory respite care or school holiday and vacation coverage. Another parent added, "Summer is a very critical time for a parent who works and has children with disabilities because there is no school. They have an additional six hours on hand, and you really have to work and shift with your spouse. Otherwise, you get financially ruined."

A third area of service provision which parents extensively discussed was **education** for their children. Although school personnel provided the principal source of supervision and education, parents expressed the following concerns regarding educators: they were not informed about their child's disorder; nor were they responsive to their children's special needs, and educators had stressful relationships with family members. Parents noted that they spent hours away from work in school meetings because staff did not know how to handle their children. One parent in particular said, "For my daughter who does most of the acting out, the crises...always happened at school. So for me it meant rearranging my work schedule and making the time to meet with schoolteachers, principals and counselors. Sometimes there would be six to eight professional in the room trying to figure out what to do with this child and setting up a new IEP. So I had to drop things and be able to work with the school people

## SUPPORT FOR WORKING PARENTS OF CHILDREN WITH SERIOUS EMOTIONAL DISORDERS: A WORKING MODEL FOR INTERVENTIONS

**PROBLEM STATEMENT:** Although as many as 5–10% of employed parents care for a child who has a severe emotional disorder, and who is under the age of 18, there are inadequate resources available to maintain a satisfactory balance between work and family responsibilities. Most notable, resources for child care are lacking.

**GOAL:** To promote satisfactory work and family life and to ensure that employed parents are able to access and afford adequate and sufficient child care and family support resources and services.

OBJECTIVES	INPUTS	INTERVENTIONS	OUTCOMES
<p><b>CHILD CARE</b> To ensure that supervision of children with serious emotional disorders is available and adequate</p>	<ul style="list-style-type: none"> <li>• Information on children's specific conditions</li> <li>• Adequate pool of child care providers</li> <li>• Financial subsidies for child care</li> </ul>	<ul style="list-style-type: none"> <li>• Training of care providers by parent groups</li> <li>• Resource and referral lists of trained providers</li> <li>• Individualized care plans for each family and child with serious emotional disorders</li> <li>• Funding distributed for child care subsidies</li> </ul>	<ul style="list-style-type: none"> <li>• Adequate, affordable care is available for children with serious emotional disorders</li> <li>• Care is of high quality and individualized to meet the children's needs and those of their parents.</li> </ul>
<p><b>PARENT EMPLOYMENT</b> To make available satisfactory and satisfying employment for parents of children with serious emotional disorders.</p>	<ul style="list-style-type: none"> <li>• Family-friendly employers and work sites</li> <li>• Flexible and adequate benefits packages</li> <li>• Flexibility built into work schedules</li> </ul>	<ul style="list-style-type: none"> <li>• Education of employers and co-workers about the needs of families with children having serious emotional disorders</li> <li>• Personal or employment counseling for parents of children with serious emotional disorders</li> </ul>	<ul style="list-style-type: none"> <li>• Parents satisfied with their employment</li> <li>• Income needs of families met.</li> </ul>
<p><b>SCHOOLS</b> To foster positive, appropriate and responsive educational experiences for children and employed parents.</p>	<ul style="list-style-type: none"> <li>• Training of school staff on child-specific conditions</li> <li>• Staff and structure in schools to manage behavioral crises</li> </ul>	<ul style="list-style-type: none"> <li>• Training of school personnel on practical aspects of children's disorders</li> <li>• Establishment of school crisis management teams to deal with emotional or behavioral crises of children</li> </ul>	<ul style="list-style-type: none"> <li>• Better educational experiences for children with serious emotional disorders</li> <li>• Fewer interruptions of parents at the workplace for child management issues</li> </ul>
<p><b>TRANSPORTATION</b> To make adequate, safe, and accessible transportation available to meet needs of children and working parents.</p>	<ul style="list-style-type: none"> <li>• Adequate pool of providers of transportation for child- and family-specific needs</li> </ul>	<ul style="list-style-type: none"> <li>• Training of providers for work with children having emotional disorders</li> <li>• Subsidized private transportation as an alternative to public conveyances</li> </ul>	<ul style="list-style-type: none"> <li>• Children with emotional disorders are safely transported to school and activities</li> <li>• Parents spend fewer hours in transportation per week.</li> </ul>
<p><b>FINANCIAL RESOURCES</b> To secure adequate financial resources and employment benefits to provide for child and family needs</p>	<ul style="list-style-type: none"> <li>• Adequate and affordable insurance</li> <li>• Entitlement programs which subsidize child care and supportive services for families having children with serious emotional disorders</li> </ul>	<ul style="list-style-type: none"> <li>• Training of human resource personnel of public and private sector on family needs</li> <li>• Advocacy for legislation for financial supports.</li> <li>• Advocacy for changes in child care tax law</li> </ul>	<ul style="list-style-type: none"> <li>• Parents can afford quality child care experiences and mental health treatment</li> <li>• Parents have incentives to remain employed</li> </ul>
<p><b>HOUSEHOLD TASKS AND MANAGEMENT</b> Ensure satisfactory household management and accomplishment of homemaking tasks.</p>	<ul style="list-style-type: none"> <li>• Family members' efforts to accomplish housekeeping tasks</li> <li>• Paid help to complete specific tasks</li> </ul>	<ul style="list-style-type: none"> <li>• Individualized care plans for household management</li> <li>• Training and funding for household services providers</li> </ul>	<ul style="list-style-type: none"> <li>• Families live in less stressful and more comfortable surroundings</li> <li>• Parents can take on a more extensive work schedule</li> </ul>

quite intimately in dealing with her behavior.” Family members reported that they became experts in the Individuals with Disabilities Education Act (Public Law 101-476) and supported others facing challenges in the educational system. When their children’s behavior was disruptive to school programs or the child’s emotional state was not manageable by teachers, parents stated that they were called at work and summoned to school to retrieve their children and deal with the problem. Although several parents spoke of their admiration for school personnel who were well equipped to care for and educate their children, this was the exception. More frequently family members discussed strained relations they had with educators and school administrators, and stated that schools were not set up to deal with employed parents.

**Transportation** of their children to and from school, appointments, and activities is the fourth area of services perceived as crucial by employed parents. The vast majority of family members reported that they themselves had to provide all transportation for their children with emotional problems. Even though other children with disabilities were transported to school in buses, children with emotional disorders were often excluded from school district buses due to their behavior. One mother expressed her experience; “...my older daughter...managed to get thrown off every bus system she was ever on. I rode the bus with her for a few weeks... and clearly she was a troublemaker. I would be sitting right there beside her and it was still a problem. Transportation problems were a hassle.” When children with serious emotional disorders were allowed on district buses, parents reported that they had to supervise the child’s departures and arrivals home.

Alternative means of transportation to school and activities, such as public transportation and carpools, were not seen as viable options. Therefore, most parents took considerable time out of their workdays to drive their children to school, activi-

ties, or doctor’s appointments.

The fifth domain, **financial assistance** was another area parents’ expressed their concerns. Several family caregivers discussed the inadequacy of their financial arrangements to meet their children’s needs in such areas as mental health treatment, child-care and home services. A few reported that wraparound programs provided financial and material assistance which helped them retain employment and meet their children’s special needs.

**Household tasks and management** was the sixth domain of concern discussed by the parents. Many employed parents reported that they simply did not have help with household tasks, even though they were employed 40 hours a week or more. This was due to their lack of discretionary funds and their concern about admitting housekeepers into their homes who were unprepared to meet their children’s special needs. However several parents reported that individuals were found who could provide adequate household management services, and emphasized the contributions these workers made to the quality of their family life.

Family members reported very different paths toward achieving fit between the demands of work and family life. Some of the focus group participants settled into a “military routine,” and held to a regimented schedule, which they perceived, worked for their families. Other families achieved fit through viewing their work and family lives as pieces of a complex puzzle. Assistance was hired to reduce work, provide child-care, transportation, and decrease home care demands. Compromises were made in work aspirations, standards for home care, and leisure activities. A parent noted, “I could have worked in international sales because I know different foreign languages, and I unfortunately had to reject this opportunity. I would have accepted the job if I did not have a disabled child. ...I feel that I could not work to my fullest potential intellectually or professionally because I just had to look

for my son’s welfare first.” In addition, several parents stated that the solution to the challenges regarding work, leisure activities and home care were never final since their children’s mental health and developmental changes produced a different set of challenges on a daily basis.

Barriers to achieving a fit were often set up in the communities and organizations within which the employed parents worked. Fragmented services and school systems denied their children certain educational and transportation opportunities because of their emotional or behavioral disorders. Unsympathetic supervisors and co-workers expected employed parents to have their family lives “under control”. Needless to say the work place provided little support.

These findings underscore the need for the development of greater support for families with employed caregivers. More trained child-care providers must be available along with suitable transportation services. Educators must recognize the need for parents to retain employment and provide school crisis teams to care for children when their behavior exceeds recognized classroom limits.

The parents’ responses in the study, Support for Working Caregivers strongly suggest that families and service providers advocate and educate employers regarding the challenges of finding a fit between work and family life for families with children with disabilities. Barriers to employment will come down when employers provide improved benefits in such areas as child care subsidies, flexibility in the use of sick leave, and permit increased flexibility in work schedules.

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## BALANCING BEHIND THE SCENES: COMBINING WORK, FAMILY AND DISABILITY

Of parents with or without disabilities, the subset who can report having a well-orchestrated, healthy balance between work, family, and individual activities comprise a very select and fortunate group indeed! And these are the parents from whom we could learn a great deal. This article was written (1) to introduce and explore some of the factors that affect the work-family fit within a family in which one or both parents have a disability and (2) to suggest ways to cultivate, nurture, and maintain a good fit within these families.

Recent studies estimate that there are at least 8.1 million American families with children in which one or both parents have a disability (Toms-Barker, & Maralani, 1997; and LaPlante and Miller, 1992). Despite the challenges around acquiring statistics, LaPlante (1991) estimated that these families comprise 10.9% of families in the United States.

Linda Toms-Barker and Vida Maralani (1997) of Berkeley Planning Associates surveyed over 1200 parents with disabilities for the Research and Training Center on Families of Adults with Disabilities at Through the Looking Glass. Among the many important results of this national survey, the authors discovered that, when compared to other disabled adults who responded, disabled parents are more likely to have attended college and to be employed. They also tend to have correspondingly higher household incomes than other adults with disabilities, yet their average income is substantially lower than that of nondisabled parents. Additionally, cost was mentioned as the greatest barrier to parents having the housing, personal assistance, child care and adaptive parenting equipment they needed.

In an effort to gather preliminary data about the work-family fit in families in which at least one parent has a



disability, I interviewed four professional working mothers who have physical disabilities.

The first mother is an occupational therapist and consultant for the National Resource Center for Parents with Disabilities at Through the Looking Glass. She has two children who are now in late adolescence and early adulthood. This mom has cerebral palsy and has also had a stroke. During our interview, she posited that parenting, more than working, may help parents with disabilities integrate fuller into society by virtue of the child's activities. "Once children are in school," she elaborated, "this becomes an important linkage for all concerned because parents, school staff, and children can get acquainted with the disabled parent and can see this parent in an ordinary setting."

The second mother is a graduate school professor and research consultant at Through the Looking Glass, and also a mother of two children ages 8 and 11. This mother has post polio syndrome. She recalled that, while she was pregnant both times, she needed to reduce her hours at work earlier than expected because of her disability. Her recovery from childbirth was also a lengthier course than she anticipated due to her disability; five months was the minimum amount of time that she needed. Her advice for many expectant parents with disabilities, especially if pain, fatigue and

/or weakness are involved, is to arrange for accommodations and support early.

This mother thoughtfully pointed out that keeping a healthy balance in any family requires money, time and energy. Any family is in trouble when they lack adequate amounts of all three of these elements. "Disabled parents," she believes, "must be very honest with themselves about how much time, money and energy they have." Knowing exactly the kinds of support and other resources

they may need can help them to have a *proactive* stance in their efforts to locate and secure these things.

Working and parenting with disabilities both involve performance pressures. This mom and her family together help one another in prioritizing various activities, and in saying 'no' when necessary. She has learned through her life experiences that "there is nothing that cannot be cancelled—except one's children."

The third mother interviewed is a member of the clinical services staff at TLG. She is a single mother of an 11-year-old boy and has osteogenesis imperfecta, or "brittle bones." This mom began our interview by emphasizing her strong work ethic as a major aspect of her identity. She has worked since the age of 16 and later worked for seven years in the computer industry. Despite the good salary, she decided to leave this field and have a child. But because her disability is genetic, she went through genetic counseling. It was this experience that got her interested in the mental health field.

Her decision to have a child was the first time she ever felt "beat up" for having a disability. Prior to genetic counseling, she did not identify with disability culture or with the disability community. Before she knew it, she was a new and single mother, a graduate student in counseling psychology, and she was starting a new

job. She felt thankful about finding a day care and preschool program for her little boy where she knew he would be safe, he could eat hot meals, and he would advance to elementary school with the same group of children. This mother stressed that "...You must have a system in place—ideally with school and work environments—that are flexible, supportive, and open to dealing with disability-related issues when they arise."

The fourth mother practiced as an attorney prior to becoming a computer programmer for a large bank. She is the mother of a 9-year-old son and has a spinal cord injury due to an accident when she was 14. Shortly after her son was born, her husband quit his job and took primary care of their baby once she returned to work. This mother did not want to stay home, and remembered that it was easier for her husband to do the baby care. All along, she has felt that her family has had "a pretty regular life." She seemed to be a bit reticent in the interview because, as she stated, "our family life is not centered around my disability." According to this mom, they may choose certain types of family recreational activities over others because of her disability, but that's about it. She concluded that, at times, there might be slightly more to juggle (in relation to the combination of work, family and her disability), but, for her, the work-family fit appears to be just the way she and her family like it.

### PROGRAM POLICY AND SOCIAL IMPLICATIONS

For adults in our society, work is very significant to self-esteem. A work life enables parents to have adult contact and interaction. One of the mothers in this article pointed out that working can be a break from family life and children's energy levels: "All parents need breaks!"

Children reap the benefits of economic stability and security in the home as well. If their parents work, children also learn that, both inside and outside of the home, their parents are productive members of soci-

ety. As they grow, children come to realize that their parents disability is but one part of their identity.

In order to blend work, family and individual lives smoothly, information about and access to disability-appropriate resources and services—at work, in school, at home, and in the community—are absolute essentials. Employers, health care and other service providers occupy crucial roles in promoting a well-balanced work-family-disability mix.

### REFERENCES

- LaPlante, M. S. (November 1991). *Disability in the Family*. Paper presented at the annual meeting of the American Public Health Association, Atlanta, GA
- LaPlante, M. S. and Miller, K. (1992). *People with Work Disability in the United States (Disability Statistics Abstract No. 4)*, Washington, D. C.
- Toms-Barker, L. and Maralani, V. (Final Report; July 1997). *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities*. A publication of the Na-

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**THROUGH THE LOOKING GLASS** offers a wide range of services for families in which one or more members—parent or child—has a disability. Clinical services, support groups, specialists in pregnancy and birthing, adaptive parenting equipment, and legal guidance in custody or adoption cases are offered. TLG produces a free national newsletter and houses the first National Resource Center for parents with disabilities. (800) 644-2666 voice; local or international callers (510) 848-1112; or [www.lookingglass.org](http://www.lookingglass.org).

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## INCLUSIVE CHILD CARE CONTINUED

subsidies, Emlen found that 222 of the parents had children with disabilities. Of the 222 parents with children with disabilities, 73% responded to the statement, "I had difficulty finding the child care I needed." compared to 56% of the total sample of 2,461 parents. Though these surveys represent only a fraction of the employed parents of children with special needs, they appear to point out that parents have concerns about community-based child care. Fortunately, since the passage of the American with Disabilities Act in 1990, there has been a growing recognition that children with disabilities have equal rights to participate in community-based child care settings. As seen from the examples above, legal mandates are not sufficient to guarantee access to suitable child care options for every family.

Because of the issues listed above regarding community-based child care, state and national child care projects have been created to assist child care providers' efforts to accommodate the needs of children with disabilities. Beginning in the mid 1990's individual states in partnership with tribal authorities formed inclusive child care planning teams consisting of administrators of child care agencies, child care providers, disability service coordinators and family members. The teams have worked toward comprehensive plans that insure that children with disabilities have access to child care services.

As an example, the state of Oregon has implemented an Inclusive Child Care Pilot Project. The Oregon Developmental Disabilities Council and the Oregon Child Care Division are collaborating on the pilot project to maximize access to community-based child care settings for children with disabilities. Currently, the Inclusive Child Care Pilot Project serves three counties and tribal members in the service areas of the Confederated Tribes of Grand Rhonde and the Confederated Tribes of the Siletz. The



*Illustration by Maryanne Brennan*

project will provide child care subsidies to family members of children with disabilities. Eligibility for a subsidy is based on a family earning less than 85% of Oregon's median income (presently around 39,300 for a family of four). Small grants will be offered in addition to the subsidies to child care providers to target school-aged children with special needs.

In 1997, the first national project addressing inclusive child care was launched by the Department of Health and Human Services Child Care Bureau. Jennifer Joy of the University of Connecticut, Division of Family and Child Studies noted, the catalysts that fueled the national project, Map to Inclusive Child Care included a forum, *Passages to Inclusion* that took place in 1995, and the Child Care Bureau and the Administration for Developmental Disabilities strong interest in addressing inclusive child care on a federal level. The project, Map to Inclusive Child Care provides an opportunity for states to benefit from technical assistance in their effort to provide community-based child care services to children with disabilities.

Joy explains that a state must apply and be selected to participate in the project. The following represents a summary of the application process. As a part of the application procedure, a designated state team with a liaison must be selected and include: families with children with disabilities, state administrators involved in child care, providers of child care services, and representatives from organiza-

tions that provide services to children with disabilities. Additional areas in the application include: the state's reason for participation in the project, documentation of current efforts to accommodate special needs children in child care settings and the state's long-term commitment to inclusive child care. Also, resources in the state must be identified to demonstrate the state's ability to offer support to sustain inclusive child care upon completion of the project.

Joy also adds that once a state has been designated as a participant in the project, a two day strategic planning workshop is conducted to assist state teams in creating inclusive child care plans that fit with their individual state's circumstances and needs. The Map to Inclusive Child Care Project provides services to state teams through on-site visits, telephone conferences, referrals to other information sources and via a national conference with participating states and national child care consultants and legislators.

Each of the ten states has the opportunity to plan an activity or event which supports inclusive child care. For the next two years, ten states per year will be added to the Map to Inclusive Child Care Project participants. For 1999, the ten states currently formulating inclusive child care community events are: Region I-Massachusetts, Region II-Puerto Rico, Region III-District of Columbia, Region IV-Florida, Region V-Illinois, Region VI-Louisiana, Region VII-Missouri, Region VIII-Colorado, Region IX-Nevada, Region X-Washington.

The availability of community child care programs for families with special needs children remains limited. Change has begun on a state and national level through inclusive child care projects to insure that children with disabilities have equal rights to access child care services regardless of their disability. However, progress is slow. Therefore, it remains critical for family members and profession-



als concerned with children's mental and physical health to work together to ensure that children with mental, emotional, behavioral or physical disabilities are as eligible as other children to be served in community-based child care settings. Further, training of child care providers must be a high priority in order to work effectively with children with disabilities. With increased political, economic, and institutional change, working families with children with disabilities can hopefully find suitable child care giving them peace of mind while at work or school.

#### RELATED REFERENCES

- Butler, T. (1997). *Child care for children with disabilities: A state and tribal approach to problem-solving*. Salem, OR: Oregon Developmental Disabilities Council.
- Child Care Bureau. (1997) *Passages to inclusion: Creating systems of care for all children*. Monograph for State, Territorial and Tribal Administrators. Washington, DC: U.S. Department of Health and Human Services.
- Emlen, A. C. (In Press). *Quality of child care and special needs of children who have emotional or behavioral problems*. Paper presented at Building on Family Strengths: A National Conference on Research and Services in Support of Children and their Families. Portland, OR.
- Emlen, A. C. (1998). *AFS Consumer Survey: From parents receiving child care assistance*. [Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, OR 97207-0751.]
- Inclusive child care pilot project launched (1999, June). *The Oregon Clarion*, 5, (No 4).
- National Child Care Information Center (1999a). *Child Care Inclusion Project for Children with Disabilities*. In *Child Care Bureau, Child Care Technical Assistance Network*. [On-line] Available: [nccic.org/cctan/abtcttan](http://nccic.org/cctan/abtcttan)
- National Child Care Information Center (1999b). *Special needs rates: Supporting inclusion of children with disabilities in child care programs*. [On-line] Available: [nccic.org/pubs/specneed](http://nccic.org/pubs/specneed)
- Olufokunbi, D., & Boothroyd, R. (1999, June). *The differential impact of welfare reform on the quality of life of low-income women: Racial and ethnic comparisons*. Paper presented at Building on Family Strengths: A /National

Conference on Research and Services in Support of Children and their Families. Portland, OR.

- Rosenzweig, J. M., Brennan, E. M. & Ogilvie, A. M. (1998, March). *How parents balance work and family responsibilities: A qualitative study*. Paper presented at the Eleventh Annual Research Conference of the Research and Training Center for Children's Mental Health, Tampa, FL.
- Warfield, M. E., & Hauser-Cram, P. (1996). *Child care needs, arrange-*

ments, and satisfaction of mothers of children with developmental disabilities. *Mental Retardation* (34), 294-302.

- Whitney, T., Groginsky, S., & Poppe, J. (1999). *Funding inclusive child care*. *State Legislative Report*, 24 (1), 1-11.

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## FINDING QUALITY IN-HOME CARE

In-home care for children with disabilities is an option frequently overlooked by working parents because of their unfamiliarity with how to locate a quality in-home caregiver. To find an in-home worker who goes beyond the call of duty (e.g., helping with homework, fixing meals and playing with the child) and cares for the child in a way that integrates him/her into the community (e.g., activities outside the home) is truly a priceless caregiver. By having the child spend time in formal and informal community activities, a child with special needs has the opportunity to provide gifts to others.

The following article will address how to find a quality in-home caregiver for school-aged children with emotional, behavioral or mental disorders. The process to hire, train and supervise an in-home worker will be described using personal experiences and insights from my family's experiences with in-home caregivers for our 11 year old child with autism. A unique aspect of our situation is that my husband has a chronic progressive form of multiple sclerosis which has not allowed him to work outside the home for several years. My role as sole provider is not likely to change. Therefore, our need for a quality in-home caregiver for our son is important.

### FAMILY NEEDS

By taking the time to investigate your family needs, the process of finding a caregiver becomes easier. One option is to begin by doing a mental inventory that explores who you are as a family. The following are examples of questions you may want to explore while doing an inventory of your family's needs.

- Does your family operate more comfortably with routine or less structure?
- Is your lifestyle casual or more formal?
- Is the atmosphere in your home more serene or lively?

- Does your family life include religious rituals on a regular basis?
- What are your family values?
- Do you prefer someone who has similar values and/or a lifestyle to match your family's lifestyle?

Based on this initial assessment, you may want to make a list of the personal qualities you desire in an in-home worker that would blend with your family's life. The following represent examples of qualities we look for regarding an in-home caregiver. We want a person who is organized because of our son's autism and our overall family structure. On the other hand, we want someone who is comfortable with spontaneity since we tend to make last minute plans. Additionally, a caregiver who is playful and enjoys humor fits well with our family. To have a clear picture of your family's needs and the qualities you are looking for in an in-home caregiver assists one in creating a job description.

### JOB DESCRIPTION

A job description to locate an in-home caregiver is developed based upon your family's needs and how you want to present your child and his/her disability. Some parents prefer to protect their children at home from the attitudes of strangers. Others support the integration of their children into the community. It is important to be clear on what you expect the in-home caregiver's role to be with your child.

It is a good idea to prepare a job description that clarifies required



tasks and approximate work hours. When applicants respond, you will be ready with a list of duties and expectations. We have revised our list several times due to experience with prior caregivers and our child's development. Prior to designing a job description, other questions to ponder may include:

- Will the position be served best by one person or as a job-share arrangement?
- What time commitment do you expect of the caregiver?
- Will the worker support your child with challenges and work with siblings?
- Is housework required?
- What additional duties are included e.g., prepare school lunch, supervise personal hygiene, transport to lessons, clubs, therapy appointments, monitor prescriptions, etc.?
- Describe the way you teach and/or discipline your child.
- Will the worker attend IEP meetings?
- What unexpected situations might arise in your family e.g., occasional late nights, school closures, vacations, family emergencies, illness?

### ADVERTISING FOR AN IN-HOME CAREGIVER

After creating a job description and identifying characteristics you desire regarding an in-home caregiver, the next step is to advertise for a quality worker. Be creative, spend extra money on the design of the flyer, you will increase the job's appeal, and potentially screen out unqualified applicants. In the advertisement, use positive descriptors to emphasize the potential rewards of working with your child, and select a few key words to highlight in the flyer. Examples of advertisements include:

Child care for **delightful boy** (11) with autism. Experience preferred. Fun, non-smoking home. Need own car. Refer-

ences required. Good student schedule 123-4567

**Help develop community connections** for teenage girl with emotional challenges. Looking for positive, creative person wanting to “make a difference” in her life. Good driver, references. 123-4567.

Once the flyer is complete, be creative about where you place your advertisement. For example, our son is on a special diet so we advertise at natural food stores in addition to college campuses and the local newspaper. Other families advertise in places of worship and utilize caregiver placement agencies.

### SCREENING APPLICANTS

Before receiving calls from applicants, you may want to consider how you will screen them e.g., by phone contact or through a resume. Our family uses the phone call as a way to screen people. In the initial screening process, it is important to ask the applicant basic questions that will help narrow the search for a quality in-home caregiver. Also, during a phone conversation, some applicants make requests that may not directly benefit your child e.g., to bring a child into your home or offer to watch your child in their home. My rule of thumb is to screen-out people who make suggestions that do not appear to assist my child or family.

When people call, the following areas are usually covered in our screening process. Our expectations of a caregiver e.g., having a car, related experience, available hours, a non-smoker and a one year commitment. The described expectations are essential for our family, and for this reason, we are unable to alter our expectations. Once we’ve responded to the applicant’s questions and shared our expectations, we decide whether to continue the conversation with the prospective employee. If we have an interest in talking further, we share a typical day in our family, referencing the list of duties (discussed earlier in

## MARK YOUR CALENDARS

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the article), and explore the applicant’s time commitments and future plans.

After covering the above areas, if the potential employee fits with our family’s expectations and s/he expresses an interest in the job, we schedule an interview. However, prior to discussing the interview, it is important to decide where you would like to have the meeting e.g., in your home or a public place. Also, to remind the applicant what to bring (e.g., personal/professional references, a driver’s license, car insurance face sheet and a resume) is helpful.

### INTERVIEWING

In the first meeting, my husband and I talk to the applicant without our son. We create a friendly atmosphere during the interview process by using humor, casual conversation and a beverage. Applicants give more accurate first impressions, if they are less nervous. After introductions and the opening conversation, you might want to ask the applicant if s/he has any questions since the phone contact. Encourage the person to ask questions throughout the interview. I feel more comfortable when someone demonstrates creativity and initiative by asking questions. Often an

interviewee will ask questions that pertain to his/her particular situation e.g., potential time conflicts, a previously scheduled vacation, activities to do with your child and gaps in work experience.

After the candidate’s questions have been answered, give the applicant the opportunity to read the job description for clarification, and to consider if the duties are acceptable to him/her. The following represents some possible questions to ask regarding the duties you list e.g., What appeals to you most on the list? What tasks are least desirable to you? What do you think needs to be added to the list? From this inquiry, you can tell if the candidate has an organized approach. You can also ascertain an applicant’s willingness to question something that is not clear. Once the interviewee reads the list of duties, we ask if there are any concerns. You may want to revisit potential concerns later in the interview.

In addition, it is also important to acquire a detailed work history e.g., job history, relevant work experience (volunteer or paid), schooling and life experiences that enhance the applicant’s suitability for the job. Do not hesitate to inquire about time gaps in work, repeated job changes or any-

thing related to prior employment.

Some other questions you might ask include:

- Talk about a time you said no to an employer.
- What has been your most difficult challenge in a job and how did you manage the situation?
- Caregiving is a demanding and rewarding job. How will you handle the demands?
- What is your experience with a child's difficult behaviors?
- What do you think is the most effective discipline?
- What forms of discipline have you used in the past with children?
- How do you handle conflict with a child?
- Would you consent to a criminal check and an inquiry into your driving record?
- If the applicant shows reticence to answer the above questions, I would not advise hiring this applicant.

Along with the above areas, an assessment of the applicant's experience with your child's particular disorder (e.g., ADHD, Bipolar, Tourette's, OCD or Anxiety) is critical. I would encourage you to focus on whether a candidate can manage him/herself when a child presents difficult behaviors. Does the candidate remain in control of his/her emotions and not take the behaviors personally? Also, if people seem overly concerned with compliance, I screen-out these potential caregivers. I emphasize to the applicant that I want a worker who uses positive behavioral methods, and seeks to understand my child's needs and behaviors.

When you have decided on a likely candidate, have them provide references from past jobs and other life experiences. Ask the candidate for people s/he has known over a period of time who will shed light on her/his character, stability and/or background e.g., parent of a best friend, family neighbor, a school guidance counselor or instructor.

Along with references, a criminal check and an inquiry into his/her driving record would be another way to finalize your choice of a worker. The person you hire will be an intimate household member and entrusted to care for your child. When selecting a caregiver, we error on the side of caution.

After we are comfortable with the applicant, the person then meets our son. It is helpful to observe how the initial encounter between our son and the person goes. We also notice how our pets react to the interviewee, and how the person responds to the animals. The comfort of our family members (child and pets) with this new person is a key factor in hiring a caregiver.

## COMPENSATION

Salary is often discussed during the phone contact and the interview. Worker pay is based on what is feasible for your family. However, keep in mind that work with children with mental, emotional or behavior disorders can be demanding. In order to find qualified people, it is important to distinguish between the cost of in-home care for children with disabilities and the general rate for child care. If it is possible, begin the in-home worker's pay slightly below the highest wage you can afford. Then you have the option of giving the worker periodic raises to reward effective work, and to promote incentives for the in-home caregiver to stay longer. Training with pay is another incentive you can offer the worker.

Besides the rewards mentioned, other possible benefits might include e.g., vacation or sick days, medical insurance, assistance with car insurance or use of a car. Families may also consider bartering arrangements e.g., room and board for a specific number of hours worked and trading services.

## ORIENTATION AND TRAINING

During orientation, the candidate acquaints him/herself with the routine of the household and gets a sense

of a typical day. We do not finalize a job offer until the worker experiences our routine for a few days, and everyone feels comfortable with the arrangements. Also, in the initial phase of orienting the worker, it would be worthwhile to have the person observe the current caregiver and ask questions.

After observing for a few days, you might want to ask the in-home caregiver for his/her impressions about working with your child, offer the worker feedback and provide any further information that might help with orientation. We consider our son's input regarding the new caregiver important, too. Additionally, during the training process, the current worker can observe and make suggestions to the new worker while s/he is in the role of the caregiver. Having the two people work as a team allows your child more time to acclimate to a new person.

Along with on-the-job training, we strongly encourage caregivers to continually increase their knowledge of autism. At our expense, we provide access to relevant articles, tapes, newsletters, books along with upcoming workshops. Another means for the worker to stay informed of autism as well as our child is to attend IEP meetings, not only to remain apprised of school issues, but also to communicate information regarding our child to school staff. If meetings occur outside of the regular work schedule, then we pay the in-home caregiver for overtime.

One last element of the orientation involves providing the in-home caregiver with a written medical release form in the event you can not be reached in an emergency. You can acquire free, blank release forms from most hospitals. Besides the release form, it is imperative that the in-home caregiver be trained in first aid techniques.

## ONGOING SUPERVISION

In our situation, we have two people who job share which requires effective, ongoing communication for them to work collaboratively as a

team. It is important for them to meet monthly to problem-solve, share information and define priorities. Our workers utilize an “at-home notebook” to communicate with each other regarding e.g., unique approaches tried, specific challenges and day to day scheduling information. Also, a calendar is used to note work hours completed, and to post a daily checklist of essential tasks. We make a point to talk at the end of each day to exchange information and discuss future plans.

Another communication tool is our “home-to-school notebook”. Family, in-home workers and school personnel communicate pertinent information to each other using this easy notebook system. Once a year, the IEP team redesigns the “home-to-school notebook” sheet so the information will be useful as our son makes developmental changes.

One last area of supervision I would like to discuss involves boundaries. To find a balance between an optimal level of service for the child and your family’s boundary is challenging for the family and the in-

home caregiver. The worker is exposed to your family culture including daily stresses. The caregiver needs clear guidelines regarding when to take part in family discussions or to remain quiet. Along with the above guidelines for the caregiver, the child, parents and worker need to be clear on who is the primary caregiver when all the adults are present in the home. When do you override what the worker tells the child? Which issues does a worker deal with and which require your input? Because of the potential for confusion regarding boundaries and roles, the need for ongoing communication between the adults and child are vital.

There are many things to consider as you pursue in-home care for your child, but the satisfaction of knowing your child has quality care will be worth the effort to find a worker. If you are prepared to nurture and train a worker, the in-home caregiver’s and your family’s experience will be positive. Workers receive outstanding training, and the benefit of working with a child with special gifts. Many former in-home caregivers have taken these gifts of experience with our son

to become valuable professionals in mental health and special education. We are grateful that the in-home caregiver’s knowledge and experience in working with our family enhances human services to children with disabilities in the community.

#### REFERENCES

- Aldape, V. T. (1994). Home caregivers make a difference, *Paraplegia News*, pp. 40-41.
- American Association of Retired Persons (1992). *Staying at home: A guide to long-term care and housing.*
- Department of Human Resources Senior and Disabled Services Division (1997). *The client employed provider program: The employer’s guide.*
- Dunn, L. (1988). *Hiring in-home help: A guide for caregivers.* Good Samaritan Hospital & Medical Center.

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## THE FAMILY AND MEDICAL LEAVE ACT

Parents constantly struggle to balance their family and work obligations. This struggle is even more complex and challenging for parents of children with disabilities or serious health conditions. These parents often find their jobs jeopardized because of the need to provide care to their children. Unfortunately, the United States is still the only industrialized country without a comprehensive family and medical leave policy covering all employees. Until we adopt a national medical and family leave policy for all workers, the primary protection for working parents of children with disabilities is the Family and Medical Leave Act of 1993 (FMLA).

Enacted in 1993, the FMLA’s stated goals are to balance workplace demands with family needs, promote

the stability and economic security of families, and promote national interests in preserving family integrity. The FMLA sets a federal minimum job security standard for parents who are trying to balance the needs of their families with their workplace obligations. Although the FMLA does not adequately address all the concerns that working parents face, it does provide some recognition of the role that the family plays in times of serious illness.

The focus of this article is on how the FMLA protects working parents who have children with disabilities. The FMLA also protects other categories of employees including, parents of new-borns, adoptive parents, foster parents, spouses and children of a family member with a serious health condition, and employees with seri-

ous health conditions. There are also “special rules” that apply only to employees of “local educational agencies”. These include public school boards, and public and private elementary and secondary school employees. If you are interested in how the FMLA protects any of these other categories of employees you should contact your human resources department or an attorney. The U.S. Department of Labor (DOL) can also answer your questions. The address and phone numbers for local DOL offices are listed in phone directories. The FMLA protections apply differently to each category of employee.

You should also check to see if your state has any laws on family and medical leave. If a state law has more generous benefits than the FMLA, you are entitled to the more generous state

benefits. If the FMLA benefits are more generous than state law, you are entitled to the FMLA benefits. If you have a collective bargaining or other employment agreement that provides more generous benefits than the FMLA, you are entitled to the more generous benefits. If your benefits under an agreement are not as generous as the FMLA benefits, you are entitled to the FMLA benefits.

The text of the FMLA is found in the United States Code Annotated at 29 USCA Section 2601 et. seq. The regulations that define and clarify the FMLA are issued by the Department of Labor and are found in the Code of Federal Regulations at 29 CFR Section 825.

### WHO THE FMLA COVERS

The FMLA does not apply to all employers or employees. It applies only to **eligible employees who work for covered employers**. All state and local governments are covered employers under the FMLA. However, not all private employers are covered by the FMLA. A private employer is covered by the FMLA only if the employer engages in interstate commerce and has fifty or more employees for each work day for at least twenty calendar work weeks in the year before the FMLA leave is requested. If you are employed by a private employer who has fewer than 50 employees, the FMLA does not apply to you.

Even if you are employed by a **covered employer**, you must still meet additional requirements to be an **eligible employee** under the FMLA. You must have worked for that covered employer for at least twelve months and must have worked at least 1250 hours in the previous twelve month period at a worksite where the employer employs fifty or more employees. The twelve months do not have to be consecutive. The determination of whether an employee meets the 12 month requirement is made as of the date on which the FMLA leave is to begin.

In general, the 1250 hour requirement is intended to be construed



broadly and in the absence of time records, there is a presumption that an employee who meet the 12 month requirement also meets the 1250 hour requirement. The employer must prove that this presumption is not true. Paid and unpaid leave cannot be counted in determining the 1250 hours. The determination of whether an employee meets the 1250 hour requirement is made as of the date that the FMLA leave is to begin.

The term “worksite” is defined as the employee’s home base from which work is assigned or to which he or she reports. A worksite can be either a single location or group of contiguous locations. For example, the various buildings on a college campus or in an industrial park may be considered a single worksite. For employees who may not have a “fixed” worksite, such as construction workers or salespersons, the “home base” is either the site from which they receive assignments or the site to which they report. The worksite for employees who are jointly employed by two or more employers is the primary employer’s office from which the employee is assigned or reports.

### CIRCUMSTANCES FOR TAKING FMLA LEAVE

Once you establish that you are an **eligible** employee working for a **covered employer**, the FMLA guarantees you a total of 12 weeks of unpaid leave during any 12 month period for certain, specific reasons. One specified reason for taking FMLA leave is to care for a son or daughter with a **serious health condition**.

**Son or daughter** is defined as a biological, adopted, or foster child, a

stepchild, legal ward, or a child of a person standing in *loco parentis*. If the son or daughter is older than 18 years of age, he or she must be incapable of self-care because of a mental or physical disability. Incapable of self care means that active assistance or supervision is required for child’s daily self-care needs in three or more of the activities of daily living or instrumental activities of daily leaving.

A **serious health condition** under the FMLA has a broader definition than the term “disability” under other laws. A **serious health condition** is “an illness, injury, impairment, or physical or mental condition that involves inpatient care in a hospital, hospice, or a residential medical care provider.” The term “inpatient care” is clarified in the Federal Regulations and is broader than having to be hospitalized. The federal regulations define inpatient care as including any period of *incapacity*, which includes the inability to work, attend school or perform other regular daily activities. The incapacity must result from the serious health condition, or from treatment or recovery from the condition or any subsequent treatment in connection with inpatient care. The period of incapacity must be more than three consecutive calendar days.

A **serious health condition** also includes situations that involve treatment two or more times by or under the supervision of a health care provider; one treatment by a health care provider with a continuing regimen of treatment, a chronic serious health condition that continues over an extended period of time, a condition that requires periodic visits to a health care provider that may involve occasional episodes of incapacity. A permanent or long-term condition for which treatment may not be effective, such as terminal cancer is a serious health condition as is a condition requiring supervision by a health care provider instead active treatment. The need to receive multiple treatments such as chemotherapy or radiation is also considered a serious health condition.

The FMLA does not cover short-

term conditions where treatment and recovery are brief and which do not typically involve hospitalization. For example, in one case, the court stated that a child's ear infection did not qualify as a serious health condition under the FMLA in part, because the child's fever lasted less than 24 hours, the child did not miss daycare, and the pediatrician did not have to supervise taking the medication.

You can take the 12 weeks of FMLA leave either all at once or on an intermittent or part-time basis. Intermittent leave includes taking your leave in blocks of time or working a reduced weekly or daily work schedule. You must try to schedule intermittent leave so as not to disrupt the employer's operations. If you take intermittent leave, your employer can temporarily transfer you to a different position that is better suited to a part-time or intermittent work schedule. The temporary position must have equivalent pay and benefits as your original position.

### HOW TO REQUEST FMLA LEAVE

You are required to follow certain procedures when requesting a FMLA leave. If the need for the leave is foreseeable, you must give your employer 30 days notice. If there is an emergency or if the need for the leave is unforeseeable, you are required to notify the employer "as soon as practical," which means ordinarily within one or two business days of learning of the need for leave. Your request has to only include the reason that you need the leave and how long you anticipate needing the leave. Your request does not have to be in writing, although it is advisable to put it in writing. You do not have to use the term "FMLA"; it is the employer's obligation to designate the leave as FMLA leave.

### MEDICAL CERTIFICATION

Your employer can require that you provide certification of your child's medical condition from a health care provider. In general, the employer has to give you at least 15

## 1999 BUILDING ON FAMILY STRENGTHS CONFERENCE HELD IN PORTLAND— SUNSHINE AND A LARGE CROWD

Beth Harry, Ph.D., keynoter from the University of Miami led off the **1999 Building on Family Strengths Conference** with powerful examples of cultural reciprocity between family members and professionals in the fields of mental health, education, health and other human services. She encouraged all present to consider the needs and perspectives of family members from different ethnic backgrounds when planning, communicating, and providing services. Dr. Harry was introduced by Tom Hanley, Office of Special Education Programs, U.S. Department of Education.

The conference was attended by family members, educators, researchers, service providers, administrators and policy makers from 40 states, Canada and Guam. Emphasis in the plenary sessions was on the cultural reciprocity, family members conducting research, and the perspectives of youth who are living with challenges of racial and ethnic difference and/or of an emotional disorder.

Members of research teams from Napa and Sonoma counties in California discussed their service improvement project with a panel entitled: *Family Members as Full Partners in Evaluation*. Panelists included: Kathy Kipp and Kathleen Brady, Napa County Health and Human Services, Napa, California, and Mary Parker-Flett and Susan Lowry of the Sonoma County Department of Health Services, Sonoma, California.

Chisao Hata, Portland, and members of the *You Are Us* project described the evolution of an arts presentation and video designed to counter racism in their lives and to educate others. At the final plenary of the conference, Delfy Pe-a Roach and Jonnie Banks of Parents for Behaviorally Different Children, New Mexico, introduced four youth and young adults who described their personal challenges living with a mental health disorder. Youth panelists were Calli and James of New Mexico; young adult panelists were Betsy of Virginia and Julia of Oregon.

Topics of papers, symposia and posters included aspects of the following themes: developments in family-centered research; family-centered, culturally-competent services; and building the capacity of communities to support children and families. A majority of the presentations featured family members or youth in leadership roles as co-presenters.

Fourteen members from throughout the United States, including five from Oregon, were selected by their family organizations to receive conference stipends.

The conference was sponsored by the Research and Training Center on Family Support and Children's Mental Health; the Federation of Families for Children's Mental Health; the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

**The 2000 conference will be held April 6-8 in Portland.**

days after making this request to submit the medical certification.

A **health care provider** includes:

- a licensed doctor of medicine or osteopathy;
- a licensed podiatrist, dentist, clinical psychologist, optometrist or chiropractor;
- a licensed nurse practitioner or nurse midwife; and,
- a clinical social worker.

Any provider who the employer uses to substantiate a claim for health care benefits is also considered a **health care provider** who can provide medical certification for FMLA purposes.



The employer can use either the standard Department of Labor medical certification form, Form WH -380 as revised, Appendix B, 825 CFR 100 et seq., or its own form. If the employer uses its own form, only the following information can be elicited:

- the date that the serious health condition began,
- the health care provider's best judgement of the probable duration of the condition,
- a statement that you are needed to care for your child, and an estimate of the amount of time that you will be needed for that care,
- the diagnosis, and
- whether inpatient hospitalization is required.

If you are requesting intermittent or part-time leave, the medical certification should also include a statement that intermittent or part-time leave will assist in your child's recovery and the expected duration and schedule of the intermittent or part-time leave.

After you submit medical certification addressing these questions, your employer may not request additional information from the first medical provider. The employer may however choose a second medical provider to provide another medical opinion. The employer must pay the cost for the second opinion. If there is a disagreement between the first and second medical opinion, the employer and employee can mutually agree on a third medical provider to provide an opinion. The employer must pay for this third opinion which is final and binding.

## WHAT HAPPENS WHILE YOU ARE ON FMLA LEAVE

The FMLA only guarantees you 12 weeks of *unpaid* leave. You can choose, or your employer can require you to use up all or part of any accrued paid leave as part of your FMLA leave. Your employer is not required to allow you to use your paid sick leave to care for your child if the sick leave is not specified for such use. For example, if your employer provides paid sick leave for sick employees, the employer can deny you paid sick leave to care for your seriously ill child.

While you are on FMLA leave, your employer must maintain any existing group health care and other benefits that you had prior to taking the leave. Your benefits should continue on the same terms as if you were still working. For example, if prior to taking your FMLA leave, you were required to make payments for your group health care insurance premiums, you will have to continue making those payments. You and your employer will have to work out the method for you to pay your share of the premium. If your FMLA leave is unpaid, you will be required to comply with the COBRA provisions and pay your premium to an insurance carrier or the employer.

You are not entitled to accrue seniority, vacation time, and pension rights during the time that you are out on FMLA leave. You cannot however lose any of those benefits that you earned before going out on FMLA leave. A FMLA leave period cannot be counted as a break in service for purposes of vesting or eligibility for benefit programs. During your leave, your employer can require that you submit periodic reports on your child's medical status and your intent to return to work.

## RETURNING TO WORK

Once your FMLA leave ends, you are entitled to return to the same or an position that is *equivalent* to the one you held prior to taking your FMLA leave. Equivalent means that the position must have the same salary and benefits as did



## MENTOR GRAPHICS FAMILY SUPPORT PROGRAM

A brightly colored building with a whimsical roofline is the first stop each morning for parents of young children working at Mentor Graphics Corporation. The Child Development Center is a model full day early childhood and family support program. The program and facility have been designed to meet the special needs of working parents with young children in a full-day program. Mentor Graphics is a leading designer of electronic design automation systems.

In the early 1990's Mentor Graphics implemented a new vision for supporting working families. Plans to provide very high quality childcare and family support programs were put into action. The first onsite child care center opened in 1992. A second Center opened in San Jose in 1998. The benefits to the company include the ability to attract highly skilled employees, increased productivity and lower rates of absenteeism and turnover.

One hundred and fifty four children are enrolled at the Center located at the company's headquarters in Wilsonville, Oregon. Both full and part time spots are available. Tuition rates are competitive with the market place. Families are encouraged to take advantage of dependant care spending accounts. Scholarships are available. The company provides a subsidy of approximately 40% that bridges the gap between tuition and the cost of providing high quality care. The mission of the CDC is to make a difference in the lives of children by being a leader in the implementation and modeling of a high quality, innovative and creative early childhood program; and to respond to the broader, contemporary family needs of our employees.

Successful implementation of high quality child care and family support requires dedicated early childhood teachers who have sufficient resources and support systems. Early childhood teachers at the Center are challenged to be innovative

and think outside the box. This mandate has resulted in the design of unique program models, best practices and family friendly policies. The CDC recruits teachers with degrees in Early Childhood Education or a closely related field. Support systems that contribute to the teachers' professional development and retention in the program include a full benefit package, tuition reimbursement, and professional development opportunities that are tied to a professional development plan. There are no aides or assistant teachers at the Center. Recently the CDC has opened a limited number of positions to individuals who are experienced caregivers but do not have a degree. These teachers receive mentoring while they work towards a degree.

The Center's design also helps to support high quality care. The building, just over 15,600 square feet, is home-like with alcoves and spaces that help to support teachers working with small groups of children. The play yard is over  $\frac{1}{2}$  of an acre and is designed to take advantage of the natural wooded setting. In Oregon's rainy climate, barns with large sliding doors provide opportunities for outdoor play all year long.

Teachers work closely together on teams. Each teaching team is responsible for constructing developmentally appropriate and culturally relevant curriculum, creating and maintaining a healthy and safe learning environment and establishing partnerships with parents. Program Coordinators work as leaders on teaching teams and are part of the management team at the Center. Programs for infants and toddlers are based on primary caregiving and continuity of care. This model has been supported by findings from recent brain research, which indicates the importance of consistent relationships with nurturing adults in the lives of young children and the development of cognitive functions. A modified primary caregiving system supports families and meets the developmental needs of older children in

preschool and kindergarten classrooms.

A developmentally appropriate early childhood program fosters the development of emotionally healthy children. The caregiving climate at the CDC emphasizes caring for children as individuals and encourages positive interactions between children. Teachers use every opportunity to foster empathy and help children to learn about their own feelings and how these feelings relate to others. Cooperation, problem solving and anger management are skills that are supported daily throughout the Center. Name calling and other emotional hurting is always addressed and stopped. Children are supported as they develop a positive sense of their own self-identity and a respect for other people whose perspectives and experiences may be different from their own.

The program is designed to be inclusive of all children, including those with disabilities, and other learning and developmental needs. Teachers work with families to find the most appropriate resources and ways to support children. Depending on the needs of a child this support could include working with therapists and other outside support professionals, special equipment, and extra staff. Therapists are asked to work with children in the classrooms. This approach helps the child receiving therapy as well as other children and teachers. The goal is to for everyone to learn empathy and acceptance. Teachers have found that professionals bring expertise and ways of looking at a child's needs that benefit all children and teachers. The teaching staff have been instrumental in early detection, referral and ongoing support of children with special needs.

SUSAN PATTERSON, MA, *Director*  
Mentor Graphics Child Development  
Center and Family Support Program.  
503.685.1736

your original position.

If the employer gave pay raises to all other employees while you were out on FMLA leave, you are entitled to that same pay raise when you return to work. If the other employees received pay raises based on their seniority or length of service, you are not entitled to that pay raise unless the employer gives the pay raise to all employees on any type of unpaid leave of absence.

As with any provision however, there are exceptions to the reinstatement requirement. The first exception applies to *key employees*. A key employee is a salaried employee who is among the highest paid 10% of employees within 75 miles of the worksite. An employer can deny reinstatement to a key employee if the reinstatement will cause the employer substantial and grievous economic injury. The employer must determine whether you are a key employee and notify you of such determination at the time that you give notice of your need for leave. Your employer must notify you of any decision to deny you reinstatement at the same time that such decision is made.

Employers can also deny you reinstatement if you would have been laid off or otherwise terminated during the period of your FMLA leave. For example, if you were hired for a specific time period and that time period expired during your leave, the employer does not have to reinstate you to either that or an equivalent position.

### IF YOU DO NOT RETURN TO WORK

If you do not return to work after exhausting your FMLA leave, your employer *may* be able to recover its share of health plan premiums if the FMLA leave was unpaid. There are however two circumstances under which the employer may not recover the premiums. The first circumstance is that you are not returning to work because of the continuation, recurrence or onset of a serious health condition that meets the need for FMLA leave. The second circumstance is that

you are not returning to work for reasons “beyond your control.”

The reasons that are considered “beyond your control” include choosing to stay home with a new-born child who has a serious health condition, if you are a *key employee*, deciding not to return to work after being notified that the employer intends to deny reinstatement because of serious economic injury, and if you have been laid off while on FMLA leave.

### HOW THE FMLA IS ENFORCED

It is unlawful for a covered employee to “interfere with, restrain, or deny” a right provided under the FMLA to an eligible employee. This means that an employer is prohibited from discriminating against anyone who opposes or complains about any unlawful practice under the FMLA or who files a charge under the FMLA. An employer is also prohibited from discriminating against any employees or prospective employees who have used FMLA leave. An employer cannot use the taking of FMLA leave as a negative factor in employment actions, such as hiring, promotions or disciplinary actions.

You can file a complaint against the employer with the Department of Labor or you can sue the employer in federal or state court. You must file a complaint within two years of the last event constituting the alleged violation. If the alleged violation is will-



ful, you must file the complaint within three years. You can file a complaint with the Department of Labor in person, by mail or by phone. The complaint should be filed with any local office of the Wage and Hour Division, Employment Standards Administration, U.S. Department of Labor. The address and phone number of the local office is in your phone directory. There is no specific form of complaint required, but the complaint ultimately must be written and should include a full statement which describes the employer's acts, and which provides dates that are relevant to the acts.

An employer who is found to have violated the FMLA may be ordered to pay lost wages and benefits, damages, interest, and attorney fees. The employer can also be ordered to reinstate or promote the employee.

### LIMITATIONS OF THE FMLA

The FMLA is a first step in providing a minimum amount of job security for working parents who have children with disabilities or serious health conditions. Its limitations are significant and illustrate the need for additional legislation to address parent's concerns. At a minimum, we need legislation that will protect more employees and that will provide some minimum amount of paid leave to care for seriously ill or disabled children. The FMLA protects only about 40% of the U.S. workforce. Federal minimum job security protections must include the remaining 60% of American workers. The FMLA only guarantees unpaid leave. If employers can provide paid leave for various reasons such as, “personal business” and “mental health”, they can certainly provide paid leave to care for a seriously ill child. Providing paid leave to care for a child with a serious emotional disorder will benefit the families, employees, and employers.

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## JACK'S LIFE: REFLECTIONS ON MOTHERHOOD IN TROUBLING TIMES

One way to explain what an anthropologist does is to say that she tries to describe what it is like to be someone else. All that time spent living with a group of people unlike oneself is meant to illicit stories, anecdotes and descriptions that illuminate, at least in a partial sense, the experience of some cultural "other." In surrounding oneself with "difference," the thinking goes, one's own culture becomes more visible. I was familiar with this process of self-discovery as an anthropologist conducting research in South America, but despite such cross-cultural forays, I was entirely unprepared for the cultural immersion I experienced, quite abruptly, with the birth of my son Jack in 1998. Within days of meeting my son, I found out what it was like to be someone else: not just a mother, a stunning enough transformation in-and-of itself, but a mother of a child with disabilities.

The immersion began with a difficult pregnancy. Suddenly I was a "patient," thrust into a strange and unfamiliar culture of medicine, doctors and endless tests. I learned quickly that the language of medicine is expressed through countless acronyms; I came to understand the difference between an AFP and an NST, and could talk with the doctors about PIH, PET, and HELP. It gave us a sense of control to be able to "converse with the natives" in their language, but the testing and monitoring, and waiting, was still a powerless and stressful time. Immersed in the foreign culture of the hospital, the strangeness only exacerbated the sensation that I had lost control of my body and the health of my baby.

As it turns out, the rocky pregnancy would only be our initiation into a world I hardly knew existed before. A week after he was born, our son was diagnosed with a rare genetic condition that typically causes growth and mental retardation as well as a variety of other problems. So now my son was the patient, and we were by

turns his desperate parents and his determined advocates. Teams of specialists descended on the small isolette (a kind of NICU crib) that held our five-pound baby. The doctors talked of scientific papers they could write; they took pictures. The rarity of his disorder was cause for considerable interest and activity. Overnight his medical file seemed to mushroom.

The diagnosis was our first taste of what it was like to have a child who, for many, represented a disorder, a medical diagnosis. The contradictions between the baby we knew, responsive and sweet and beautiful, and the baby the doctors described for us as a series of "maybes" (maybe he will grow, maybe he will develop, maybe he will need this specialist or that treatment...) were painful and confusing and terrifying. Michael Bérubé writes of a similar experience with the birth of his son, who has Down Syndrome. He describes how he got to know his child as a series of test results and medical procedures before he got to hold him and know him as a baby. "When Jamie finally came home," Bérubé explains, "he came home as a thoroughly medicalized child. Not merely 'medicated,' but medicalized: to talk about him was also to talk about his procedures and prospects in medical terms, and he already had a hefty medical chart to prove it."

So one of the first questions we faced was who was this baby? Well-meaning people gave advice: "Treat him normal," said the neonatologist; "All he needs is your love," said others. We clearly favored the less clinical of his dual identities, but much as we would have loved to ignore and deny the clinical, how could we? We were his loving parents, who were proud of him and wanted others to see him first and foremost as a child, a baby, a whole person, and yet we were also his responsible guardians, his advocates, in the 1990s language of child welfare.

And so we read voraciously, but reluctantly, all the literature we could find on Jack's disorder. What had happened to other children? Who was the top specialist in the world? What tests did Jack need? It was impossible to tell from those articles what we really wanted to know: what were those children like? Did they play outside with their friends? Did they eat peanut butter and jelly sandwiches? Were they happy? We didn't really care what metabolic pathways were involved in the disorder; we wanted to know what all our lives were going to look like. We brought stacks of this literature to the specialists. "We haven't seen that one, can we copy it?" They would say. We felt like partners, like advocates. But the truth was we didn't understand much of what we read and felt overwhelmed by the responsibility of making decisions for our fragile baby.

Another anthropologist, Gail Landsman, has written about her own experiences raising a child with disabilities. She explains that while new legislation in the 1980s and 1990s has been very important in empowering the disabled and their families, many families do not feel that they have the knowledge to make such "choices" on short notice. "With no experience and few role models from their own lives, these mothers take on the tasks of negotiating individualized service plans and integrating their children with disabilities into mainstream society," Landsman writes. Ironically, the laws meant to facilitate the inclusion of disabled children in society may also contribute to a sense of isolation for the parents, she argues.

When this rhetoric of choice is combined with "professional distance," or even "professional aversion" as one author described, the parents feel even more alone in making difficult decisions. For the most part, we were grateful for the excellent and sensitive care we received from various specialists, social workers and nurses. Many of them remem-

bered our child's name and seemed to recognize how difficult our situation was. One resident who helped diagnose Jack spent a weekend reading everything she could find about the disorder so that she could answer our questions.

Nonetheless, we ultimately felt very alone in making decisions for our son about what tests would be done and what services he should receive. There was no treatment for his disorder, but there were still many decisions to make about his care. The pediatrician, the one from whom we perhaps expected the most in terms of empathy and guidance, seemed the least willing or able to give it. She seemed uncomfortable and disengaged in our presence, referring constantly to Jack's file as if she hardly remembered the particulars of his case. She called us at home only once, and that was to deliver test results that turned out to be incorrect. She seemed not to care, which confused and frustrated us, but now I see how it must have been for her, faced with demanding parents and a child who could not be fixed. Maybe she cared too much.

The other irony with the emphasis on "choice" in Early Intervention Programs and medical care for the disabled is that the term suggests that we control the things that really matter in our lives. One of the first lessons a parent of a child with disabilities learns, however, is that in fact we have very little control over almost anything of consequence. A sense of "lost innocence" is especially profound for parents who believed that doing everything right would guarantee a healthy child.

Along with the anger that parents



feel is often a sense of failure, which can be reinforced by the responses of others. Advances in prenatal diagnosis and neonatal medicine have led to the widespread belief that most disabilities, or in this case genetic anomalies, can and should be prevented. The uninitiated, who don't understand that things happen beyond our control, wanted, and sometimes demanded, an explanation. Many asked, "Didn't you have an amnio?" As if that alone would have guaranteed a healthy outcome. Even medical staff, who surely understood that amniocentesis is capable neither of diagnosing all disorders nor of preventing them, asked this question. I always answered defensively, as if I should explain how I had let this happen. Eventually I just stopped answering. We worried, as many parents must, about the value of our son's life. If a critical gene is missing or defective is the person "whole?" What purpose might their life serve? Can that purpose justify the suffering that they and their families endure? I sensed that others were asking the same sorts of questions. Was this birth a cause for celebration or despair? For us it brought both in equal measure.

After a while, people seemed to absorb the shock of it. Little blue outfits and fuzzy toys began to arrive. We took Jack to the park and to Starbucks and on rides in the car. We "treated him normal," following doctor's orders. He kept us up all night; diaper changes were calamitous and hilarious occasions. He wasn't so different after all, we said. We pressed on. We talked a lot about wanting normalcy in our lives again. Eventually, I stopped feeling dishonest when I accepted the compliments of strangers who cooed at our beautiful baby, unaware of our family drama. We were parents; we held our heads high.

I made plans to go back to work. That had always been the plan. I could do some of my work at home and I thought the time at work would help restore some normalcy to my life. My husband was working at home that year, so we only needed part-time childcare. Finding someone who was

both qualified and willing to help care for our son turned out to be a challenge, however, as we found out firsthand about the shortage of childcare for the children with disabilities. Eventually, I found a private organization that helps match specially-qualified childcare providers with parents. Still, I had to face my feelings about leaving my baby behind while I went to work. This is a familiar enough scenario—working mother returns to work with feelings of regret, guilt, and a determination to continue her career. In my case the guilt, and the sense that my baby needed me, was even stronger. Yet we felt that as a matter of survival we had to continue with the original plan or allow our lives to be totally consumed by this disorder.

I distinctly remember thinking, as I finished my first class on my first day back at work, that I had made the right choice. It felt good to be a professional for an hour, to get my mind off of the troubles at home. Moments later, however, I was told that my son had died in his sleep. I know my absence did not cause Jack's death, but I imagine I will always question the wisdom of trying to do it all. Jack only lived for three months, so my experience with raising a child with a disability is limited in some respects. But I have a keen sense of the added burdens families of children with disabilities face when balancing the competing demands of work and home.

Looking back on it now, it seems strange to me that we ever questioned the value of his life. So many lives have been changed by his brief presence that I honestly cannot remember what the world was like before Jack. We knew the value of his life even before he died and we wanted him to live, even as we grieved the loss of the baby we had hoped for and expected. As an eleven-year-old friend of the family said, "He was very quiet, but he was very loud, you know?" And that's just how he was.

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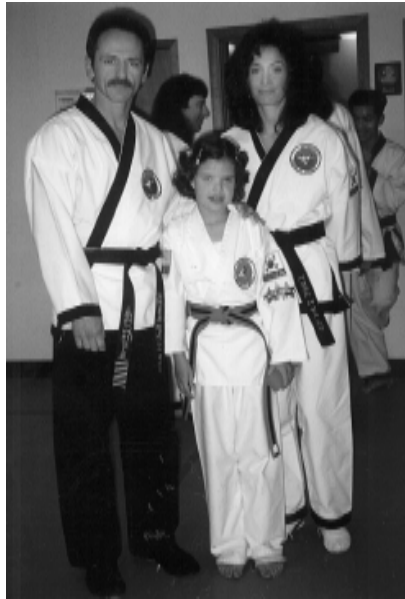
## THE ROLE OF TRADITIONAL TAEKWON-DO FOR CHILDREN WITH EMOTIONAL AND BEHAVIORAL DISORDERS

*Traditional Taekwon-Do addresses a number of important issues facing both children and adults in today's educational and family systems. With the world changing and expanding so quickly, the ability to adapt to our fast moving culture is becoming increasingly difficult. Our Public Educational system makes a valiant attempt to meet the needs of our children, who we must recognize as the future of the human race.*

*In times of old, the epitome of warriorhood was the ascendance to a higher level of thinking, managing emotions and choosing correct behavior befitting a warrior. The warrior was society's ideal person, living for all that was just and fair and dedicating one's life to the Taekwon-Do tenets of Courtesy, Integrity, Perseverance, Self Control and Indomitable Spirit. Honor was a virtue to be measured by the quality to which one lived his life and how strictly he adhered to these tenets.*

*In modern times, the warrior's code still exists in Traditional Martial Arts. The word "martial" denotes a military philosophy, which subscribes to the idea that the greatest way to achieve meaningful goals on a large scale is by mutual cooperation. Today's martial arts offer a variety of benefits and services to our young people who are struggling to adapt to confusing and chaotic times gangs, violence in the schools and more recently, murder of children by children.*

*Although modern Traditional Taekwon-Do training was inspired by ancient warrior philosophies, the life and death strictness of the training hall have been transformed into a unique place of study, motivation and goal setting. Where once the warrior would spend his life perfecting martial virtues and deadly martial skills, today's warriors dedicate their lives to the perfection of character and the unification of the body, mind and spirit. The confidence gained by good physical health, self-defense skills and recognition from peers, parents and teachers is leading our youth on a path of excellence so rare in other venues. Even school sports,*



*which are not always funded due to budget cuts, focus on the "team" effort. Although this is an important socialization asset, it does not focus on the multifaceted needs of the individual, which is so important when developing the characters and personalities of tomorrow's world leaders.*

### **Bettencourt's Taekwon-Do America**

Traditional Taekwon-Do is the Korean art of self-defense and offers a system of discipline for the unification of the body, mind and spirit. Its roots have been traced to the period between 3 A.D. and 427 A..D. As with other martial arts, the attainment of warrior status is measured by the earning of the coveted "Black-Belt". There are nine levels of Black-Belt which take a lifetime of dedication to master. The Master level is at 6<sup>th</sup> Degree and the Grandmaster levels are 8<sup>th</sup> and 9<sup>th</sup> degrees.

The 1<sup>st</sup> Degree Black-Belt (1<sup>st</sup> Dan) is seen as the beginning level of learning the "way". It is at this point that much of the basic tools are developed and honed to the sharpness needed to ascend to the higher levels of training. These higher levels include:

1. Strengthening the body, perfecting technical, skill and timing and achieving the ability to perform a major portion of these skills as "second nature".
2. Strengthening the mind by forging a training regime of discipline, maintaining a regular schedule, teaching Taekwon-Do to others, and continued goal setting. This stage also emphasizes resisting the common weakness of the mind, which create unbalance. These may include overeating the consumption of alcohol, drugs, smoking, inappropriate and or uncontrolled emotions and actions unbecoming of a Black-Belt representative of the "dojang" or Taekwon-Do school. If the mind is strong the body will follow.

Traditional Taekwon-Do also focuses on spiritual development by offering a strict system of martial virtues, tenets, and by supporting the individual's spiritual practice or religion of choice. Taekwon-Do does not subscribe to any particular religion, but rather emphasizes the spiritual discipline and practices, respected by all major religions.

Modern Taekwon-Do training at Bettencourt's Taekwon-Do America focuses on the individual needs of each student. More one on one instruction and mentorship is available due to the unique approach of learning by teaching. Intermediate and advanced students begin supervised teaching duties after about one year of training. This enables the students to more thoroughly learn his art and gives the new student the opportunity to ask questions, test his own ideas and to continue to develop his training plan on a more private level.

### **Instructor Training Program**

As with any instructor training program, the quality of instruction is dependent on the quality of training, supervision and practical experience.

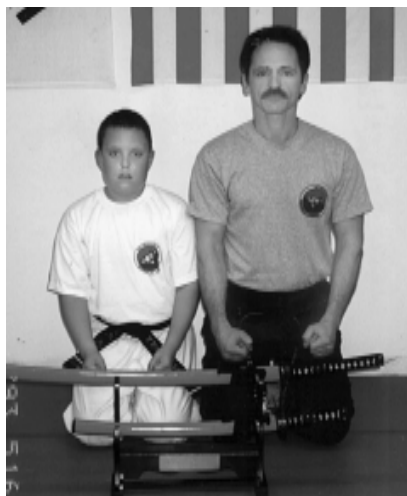
The training at Bettencourt's Taekwon-Do America, focuses on technical skills and respect of others, eliciting parents' advise and input, and developing a curriculum that will give the most benefits to its members. Traditional Taekwon-Do has become a very popular vehicle for instilling focus and motivation to strive for excellence. The instructor-training program is geared toward helping each student learn to become a teacher and a leader. The pride and confidence derived from such an experience serves as the motivating factor for many young instructors to improve their own skills and self-discipline, resulting in their becoming good role models for other students.

The program begins with a preliminary Instructor's Seminar. This outlines those qualities needed to be a good and effective role model, teacher and self-motivator. It also introduces basic requirements of do's and don'ts of effective mentorship and leadership. The most emphasized attributes are following the Taekwon-Do tenets already described, a personal commitment to excellence and a willingness to give personal time to others who are learning the "way". The "Do" in Taekwon-Do is translated as "way", a path, method, as in the Chinese word "Tao". Taekwon-Do is a way of life, designed to provide focus and purpose to all endeavors.

Weekly supervision focuses on successes, perceived failures, teaching methods, role-playing, and individual needs of students. This is also a time when these student teachers can ask pointed questions about proper execution of technique, philosophy and curriculum. It serves as an excellent forum for building the solid, unified core of our Taekwon-Do program.

Instructors are trained to be creative and flexible in their approach to each individual as personalized lesson plans are developed. This is accomplished with the following resources:

- Parental input is requested before and during their child's training.
- Anonymous requests in the "Suggestion Box"
- Staff meetings discussing issues



of students with "special needs"

- Ongoing assessment of progress and goals through evaluation and testing.
- Specialized training in recognizing teaching children with unique needs (ADD, ADHD, inappropriate behaviors, low motivation, self-esteem, impaired social skills, etc.)

### Traditional Reward System

Inherent in the Bettencourt's Taekwon-Do America reward system is short-term goal setting. This is a valuable aid to a system of successive goals that are reachable in a reasonable amount of time. The curriculum was developed by the school's President and Master Instructor, Steven Bettencourt, a 6<sup>th</sup> Degree Black-Belt who also holds a Masters Degree in Psychology. The particular curriculum is designed by age group so the feelings of competence, confidence and achievement become habit. The Taekwon-Do belt system serves this function as each student satisfies the requirements for each belt as short-term goals. As each belt is acquired, the long-term goal of Black-Belt appears more achievable. At Bettencourt's Taekwon-Do America, the belt system is as follows: white, yellow stripe, yellow, green stripe, green, blue stripe, blue and red stripe, red, black stripe and black. There are nine levels of Black-Belt.

### Other rewards include:

- Monthly achievement charts re-

ording daily achievements.

- The Youth Tip system is a reward system, which breaks down each of the six elements required for the next belt level. Each tip is color coded with special tape on their belts and recorded on the student's daily attendance card.
- Student of the Day, Week, Month and Year.
- Special recognition for outstanding achievement in a variety of areas encompassing learning objectives, teaching excellence, performance excellence, etc.
- Feature story in the Bettencourt's Taekwon-Do America newsletter.

The children's programs begin at ages 3-6 for the Tiny Tigers, ages 7-12 for the youth program, ages 13-17 for the Teen/Adolescent program and age 18 to adults. It is our experience that children as Young as 7-8 years old make excellent teachers. Peer support is a long used method for instant compatibility in many fields, and teaching Traditional Taekwon-Do is no exception.

### Issues Faced When Teaching Taekwon-Do to Children

When Children begin Taekwon-Do training, they usually begin for a special reason. The most common reasons may be:

- Needs a structured, positive environment
- Comes from a single parent home; needs role model(s)
- Acting out behaviors at home and school
- Shy, low self-esteem, depressed
- Referral from school/Mental Health Professional
- ADD/ADHD/FAE/Asperger's, MRDD, etc.
- Just plain excited about Taekwon-Do
- Therappuetic respite for both child and caregiver

The instructor will do an inventory after the first introductory "get acquainted" lesson. A goal plan is established outlining the needs of both parent and child and accord-

ing to the assessment of the instructor. This goal plan will serve as a barometer to progress as the training program is implemented. It is also important that new goals be added and old ones replaced as the learning process unfolds.

It is paramount that the instructors be consistent with approach and method when teaching each class.

Positive rewards are given every few minutes to keep each child on track and motivated. The high energy serves to motivate each child to greater levels of achievement and serves to address the relative short attention spans of young children.

Setting consistent boundaries with multiple rewards allows each child to stretch his creativity and effort in a safe environment. Each student quickly learns what behaviors are expected and acceptable in the "dojang" (Taekwon-Do school) in order to maintain self-discipline and achieve rewards. We feel that boundaries are a testable fence that makes children feel safe and secure, knowing their operational parameters. The number one rule in the dojang is "safety", especially since no contact is ever allowed in free sparring practice, promoting respect, non-violence and safety.

The instructor is challenged to find the most positive points to reward in order to establish a baseline for encouragement. As one aspect of training becomes more proficient, it can complement the less productive efforts of other areas until balance can be achieved. For instance, a well executed kick can be rewarded at a crucial moment to serve as a confidence builder to perfecting stances, hand strikes, blocks or simply an increased effort in class.

Children who are resistant to perceived authority or criticism are especially challenging. When sensitive children are perfectionists, they may respond with a deflated ego, frustration and play the victim role. They feel they do not have the ability to "do enough" and give up. They may also simply get angry when corrected. Since they learn best from construc-

tive input on progress, it is very important to establish a relationship of trust, respect and mutual cooperation. When the child feels the instructor is there to support him, is on his team and is proud of even small improvements, he is more apt to engage in more pleasing behaviors, especially for ages 3-13. Competence is so important to sensitive children, whether they react in tears, or anger, they must be treated with "kid gloves".

Above all, the Taekwon-Do experience must be fun to do, have ample rewards and noticeable benefits. Both child and parent must feel all these elements are inherent in the curriculum, lesson plan, reward system and quality instruction. When the child respects the instructor she will try her best....which is the best way to achieve her goals.

### The Challenges of Children with Special Needs

Inherent in teaching children new skills and new information should be an awareness of how differently children learn. Bettencourt's Taekwon-Do America addresses the variety of learning styles of students of different ages, maturity levels, physical body types, gender and strength. In addition, many children with Attention Deficient Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) or Fetal Alcohol Effect (FAE), are referred to our school from public schools, mental health centers

and parents of such children.

Usually, teaching styles and curriculum are designed to meet the needs of the "average" child. We have found that there really is no average child, a fact that most teachers have known for eons. Since Traditional Taekwon-Do focuses on the individual, rather than the group event, it is imperative that personal goals are emphasized.

Whereas many children can stand at attention for long periods of time, the child with ADD/ADHD can barely maintain a stationary position for more than a few seconds. This is especially evident upon first enrolling in this new and strange environment of discipline, expectation and rules, mixed with fun, excitement, and learning "cool stuff". Instructors must be aware of this fact and consistently reward positive steps toward each goal. This consistency of sanctions with respect establishes a more beneficial environment for all of the young students. Children must be contacted directly with a physical touch, or getting down on one knee to meet their eyes in order to communicate a request. It is this special effort of getting the child with ADD/ADHD to "connect" to the class drills, to her/his peers and to the instructors that brings these children to a higher level of skill than they have ever achieved before.

Instructors must also be consistent with negative consequences in

### EDITOR'S PICK: WEB-SITES

☞ <http://www.aacap.org/factsfamindex.html>  
*information for families on everything from autism to medication to eating disorders (Available in Spanish and French also.)*

☞ <http://www.grandparentagain.com>  
*web-site for grandparents raising their grandchildren which includes information about support groups, legal information, and personal stories.*

☞ <http://www.bazelon.org>  
*Bazelon Center for Mental Health Law provides information on Social Security, special education, and legal rights for mental health patients, among other topics.*

the case of disruptive behavior. When the parents and teachers share daily progressive and regressive behaviors, there develops a consistency to the child's overall program, which aids substantially to his success. The main quality required of a Bettencourt's Taekwon-Do America teacher is **PATIENCE**. The challenge of each one of the Bettencourt's Taekwon-Do America Instructors is to embody the Tenets of Taekwon-Do through diligent awareness of being a role model and mentor. It is through strong support and team effort that this is possible.

When acting out behaviors become too disruptive, children are respectfully removed from the class area, reminded of their responsibilities as role models for other children and may be given a time out. Even with all of the best efforts and intentions of the instructor, in the more severe cases, the student may be asked to leave the school until the following day or next class attended. Since actual punishment is discouraged, we focus on positive over negative reinforcement. In this way, we feel, there is much less resistance encountered in the overall positive learning experience. These children know they can

return and they know clearly what their expectations are. We feel this is the best thing they can learn about the world as they begin to adapt their learning disabilities to mainstream programs. As Traditional Taekwon-Do teachers we also see ourselves as a remedial step toward normalization behavior to help these children to acquire adaptive skills that are easily implemented to other areas of their lives, such as home, peer groups and future employment.

The Pyong Hwa Musado style of Taekwon-Do taught at Bettencourt's Taekwon-Do America is a unique blend of martial skills, respect, genuine caring and mentorship of life skills. The Taekwon-Do learning experience challenges all age groups in the unification process of body, mind and spirit. Students are taught to master their emotions by stilling their thoughts. They learn that the blending of a calm mind and a calm emotional state leads to a controlled flowing of effortless action. This is the goal of learning the "Way of the Peaceful Warrior" at Bettencourt's Taekwon-Do America.

Since ADD/ADHD may exhibit poor emotional control resulting in

acting out behaviors, we see lots of anger, aggression and frustration levels in these children. When they acknowledge a sincere desire to overcome these urges for outbursts, they become valuable partners in recognizing their signs of frustration, tension levels and inappropriate behaviors. In this way, their goal plan can be modified whenever needed, to truly become the Black-Belt they have always wanted to be. With such clear expectations and visible role models of peers and teachers, the metaphor of "Black-Belt" behavior becomes a powerful tool in helping these challenging children to reach their goals. They can also become important role models with increasingly significant teaching responsibilities, working with children with or without ADD/ADHD. The self-esteem, confidence and positive goal acquisition gained using this comprehensive approach has proven to be quite effective and rewarding to all involved in what may be the most important learning experience of their lives. Our participation in this process helps to fulfill our mission as builders of our community and making a positive difference in our society.

## CARTER CENTER MENTAL HEALTH PROGRAM AWARDS

The Carter Center's Mental Health Program named this year's six recipients for the annual Rosalynn Carter Fellowships—Mental Health Journalism. Part of a national effort to reduce stigma and discrimination against people with mental illness, the program enhances accurate reporting about mental illness and encourages journalists to expand their knowledge about related topics. "There is tremendous potential for journalists to improve the public's understanding of mental health issues", said Mrs. Carter. "They can play a critical role in reducing stigma against people with mental illnesses."

1999 Fellowship Recipients include: Pat Bellinghausen, *Billings Gazette*; John Head, *Atlanta Constitution*; Lisa Hyvarinen, *WTSP-TV*; Anne Murphy Paul, *More Magazine*; Paul Raeburn, *Business Week*; and Emil Venarec, *Business and Health Magazine*.

The recipients each of whom will receive an award of \$10,000, made possible from the contributions of various corporations and foundations, will meet at the Carter Center September 14–16 with Mrs. Carter and the Center's Mental Health Task Force to discuss planned topics of study.

For more information about the Fellowship program and future efforts of the Carter Center in the area of mental health contact: Ann Carney (404)420-5126

**MASTER BETTENCOURT** earned his *Master's Degree in Counseling Psychology in 1983. He has worked for many years as a psychotherapist, college instructor, Mental Health Clinical Supervisor, and as a consultant, specializing in Anger Management. He currently maintains a private practice called Peaceful Warrior Counseling and provides the Anger Management treatment for Washington County Community Corrections in Hillsboro, OR. He has authored a comprehensive Taekwon-Do text book and seven other books on Taekwon-Do curriculum and Anger Management. He conducts seminars on Taekwon-Do, Hapkido, Warriorship and conflict resolution. For more information he can be contacted at: Bettencourt's Taekwon-Do America & Peaceful Warrior Counseling, 2906 NE Glisan Street, Portland, OR 97232. (503)231-5474; Fax (503)231-0126. E-Mail: MUSADO2906@aol.com*



*RTC Announces New Monograph for Distribution*

## FAMILY PARTICIPATION IN THERAPEUTIC FOSTER CARE: MULTIPLE PERSPECTIVES

Therapeutic foster care (TFC) offers a community-based treatment alternative for children with serious emotional disorders in the child welfare system, in which trained caregivers provide care in family settings. In the shift away from residential treatment for children with serious emotional disorders and toward family-centered, community-based treatment, TFC has emerged as a key component of the systems of care (Meadowcroft, Thomlison & Chamberlain, 1994; Stoul & Friedman, 1986; Stroul, 1989). The development of TFC homes may also be related to child welfare and mental health professionals' increasing awareness of the mental health needs of children in regular foster care (Blumberg, Landsverk, Ellis-McLeod, Granger & Culver, 1996; Goerge, Wulczyn & Fanshel, 1994; Landsverk, Davis, Granger, Newton & Johnson, 1996; Simms & Halfon, 1994).

Associated with the implementation of the child and adolescent service system program (CASSP) principles (Stroul & Freidman, 1986; 1988) and the development of the family advocacy movement (Bryant-Comstock, Huff & Vandenberg, 1996) in the last fifteen years, there has been increasing emphasis on the participation of parents and other family members in the treatment of children with serious emotional disorders. To date, there has been limited attention to family participation where children are in out-of-home placements, even though there is research evidence that parent-child contact is associated with more rapid family reunification.

The following qualitative study (1999) conducted by Dr. Pauline Jivanjee, Dana Sieverin-Held, MSW & Julie Siepmann, MSW focused on family participation in TFC. Thirty-

five semi-structured qualitative interviews were conducted with three groups of respondents: parents of children placed in TFC; TFC providers and child welfare/mental health professionals. The study examined family participation in TFC from the perspectives of ten parents who between them had fourteen children placed in TFC, twelve TFC providers who were caring for their children, and twelve child welfare (in some cases mental health) professionals who were working with each child.

The interviews focused on the characteristics of children placed in TFC, challenges of caring for these children, and their responses to TFC. Aspects of family participation in TFC which were examined included: Parent-child contact, parent-professional communication and information sharing, parent participation in decision-making; relationships between parents, professionals and TFC providers. Professionals' and TFC providers' values and attitudes toward family participation, barriers to participation and strategies to enhance family participation were identified. Cultural and class issues in placement planning and ongoing care were examined, as well as patterns in service use before and during placement, and plans for follow-up care.

Parents varied in their responses to TFC. Some parents were appreciative of the TFC providers who reached out to them to share infor-



mation about their children and offer opportunities for contact. However, other parents were angry about the limits placed on their contact with their children and being excluded from decision-making. Also, professionals identified organizational barriers to family participation, such as large caseloads which constrained child welfare workers' time to devote to families. Another challenge to family participation related to TFC providers' lack of training to work with parents. And last, TFC providers offered a range of perspectives on their willingness to have contact with families and to support children in the retention of parent-child bonds.

This study provided parents of children in therapeutic foster care with an opportunity to express themselves regarding the care and treatment of their children. In addition, front-line professionals and providers were interviewed about their working relationships. The study also contributed to the development of a research agenda to more fully understand the phenomenon of family involvement with children placed in out-of-home care, and its long-term effects on the children's and family's well-being.

### FAREWELLS AND CONGRATULATIONS TO OUR RECENT GRADS

After receiving her Ed.D we wish **MJ. Longley** great success in her new role as Adolescent Program Manager for the South Central Foundation in Anchorage Alaska.



Kelly Blankenship

After receiving her MSW **Kelly Blankenship** left us to put her education to work in California. Both Ms Longley and Ms Blankenship greatly enhanced the capacity of this Center while they were here and will be sorely missed.

**Shad Jessen**, a stalwart member of our support staff for nine years, has left the Research and Training Center for a full-time computer support position within Portland State University. In addition to the excellent administrative support that he provided, Shad used his considerable computer skills to design and maintain an award winning web page for the Center. He also redesigned web pages for the Regional Research Institute, the Graduate School of Social Work, and the Ph.D. Program in Social Work and Social Research. We will miss Shad's contributions to many aspects of our work, from his help with travel arrangements to his ideas about improving the quality of conference materials and publications. We will also miss Shad's sense of humor and his friendship. We wish him well in his new role, and want to publicly say, "Thanks for everything."



Shad Jessen with small friend

### MONOGRAPHS

Look forward to our next monograph on early childhood mental health being produced in connection with Children's Mental Health Services (CMHS). This monograph will address mental health care for very young children (ages 0-5) and their families, and will include results of a literature review, site visits, and in-depth telephone interviews. You can look for distribution of this monograph in early 2000, along with several other volumes of the Promising Practices series (below).

The Promising Practices Initiative of the Comprehensive Community Mental Health Services for Children and Their Families Program recently published a seven volume series of monographs exploring successful practices in providing effective, coordinated care to children with a serious emotional disturbance and their families. The various practices examined include;

- Volume 1: The New Role of Families in Systems of Care
- Volume 2: Promising Practices in Family-Provider Collaboration
- Volume 3: The Role of Education in a System of Care

- Volume 4: Promising Practices in Wraparound
- Volume 5: Training Strategies for Serving Children with Serious Emotional Disturbances and Their Families in a System of Care
- Volume 6: Promising Practices in Building Collaborations in Systems of Care
- Volume 7: A compilation of Lessons Learned from the 22 grantees of the 1997 Comprehensive Community Mental Health Services for Children and Their Families Program.

The Research and Training Center produced the second volume in this series entitled *Systems of Care: Promising Practices in Family Provider Collaboration*. This monograph provides an in depth examination of the challenges participants in systems of care face as they work at family-provider collaboration, and offers examples of strategies and practices families and providers have developed in achieving collaboration.

In this monograph you will find: definition, components, and minimal requirements for family-provider collaboration, challenges to family-provider collaboration, in-depth discussions of family-provider collaboration at four systems of care, including: North Carolina PEN-PAL and FACES; the K'e Project, Navajo Nation, Sanoma-Napa County Comprehensive System of Care, California; and East Baltimore Mental Health Partnership, Maryland.

There are a limited number of these monographs available for distribution free of charge. To order Volume II please contact the Research and Training Center at (503)725-4040 (phone), (503)725-4180 (FAX) or visit our web site <http://www.rtc.pdx.edu>. This document is also available at <http://www.air-dc.org/cecp/> from the Center For Effective Collaboration and Practices.

For more information on the series please contact the Child, Adolescent, and Family Branch of the Center for Mental Health Services, Substance Abuse and Mental Health Mental, at (301) 443-1333, or the Center for Effective collaboration and Practice at (888) 457-1551/(202)-944-5400.

### TIPPER GORE PROMOTES ANTI-SUICIDE EFFORTS

*Washington (Reuters):* Mrs.Gore joined Surgeon General David Satcher in outlining new steps to promote awareness of suicide among health care workers, educators and others and to encourage people to intervene against potential suicides.

Mrs. Gore and Satcher also said they would work with communities, schools and local governments to develop by the end of 2000 a national plan to prevent suicides.

About 31,000 Americans kill themselves each year, and 500,000 are treated for suicide attempts. Elderly people account for 20 percent of all suicides, but rates have risen sharply among children aged 10-14 and among young African-American males since 1980. Gay and lesbian youth are at a greater risk than other young people of committing suicide, Mrs. Gore said.

# PUBLICATIONS

- AN INTRODUCTION TO CULTURAL COMPETENCE PRINCIPLES AND ELEMENTS: AN ANNOTATED BIBLIOGRAPHY. 1995. *Describes articles & books that exemplify aspects of the CASSP cultural competence model.* \$6.50
- NEW!** BENEFITS OF STATEWIDE FAMILY NETWORKS: VOICES OF FAMILY MEMBERS. 1998. *Describes issues, benefits, and impacts of statewide family networks in a user-friendly format with extensive quotes from family members to illustrate finds.* \$5.00.
- BROTHERS & SISTERS OF CHILDREN WITH DISABILITIES: AN ANNOTATED BIBLIOGRAPHY. 1990. \$5.00.
- BUILDING A CONCEPTUAL MODEL OF FAMILY RESPONSE TO A CHILD'S CHRONIC ILLNESS OR DISABILITY. 1992. *Proposes comprehensive model of family caregiving based on literature review. Causal antecedents, mediating processes and adaptational outcomes of family coping considered.* \$5.50.
- NEW!** BUILDING ON FAMILY STRENGTHS: RESEARCH, ADVOCACY, AND PARTNERSHIP IN SUPPORT OF CHILDREN AND THEIR FAMILIES. 1994 CONFERENCE PROCEEDINGS. *Transcripts of plenaries including keynoter Lee Gutkind, Cleopatra Caldwell, Henry Levin and summaries of paper and panel presentations.* \$8.00.
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- CHANGING ROLES, CHANGING RELATIONSHIPS: PARENT-PROFESSIONAL COLLABORATION ON BEHALF OF CHILDREN WITH EMOTIONAL DISABILITIES. 1989. *Examines barriers to collaboration, elements of successful collaboration, strategies for parents and professionals.* \$4.50.
- COLLABORATION BETWEEN PROFESSIONALS & FAMILIES OF CHILDREN WITH SERIOUS EMOTIONAL DISORDERS. ANNOTATED BIBLIOGRAPHY. 1992. \$6.00.
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- FAMILY ADVOCACY ORGANIZATIONS: ADVANCES IN SUPPORT AND SYSTEM REFORM. 1993. *Describes and evaluates the development of statewide parent organizations in 15 states.* \$8.50.
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- NEW!** FAMILY PARTICIPATION IN THERAPEUTIC FOSTER CARE: MULTIPLE PERSPECTIVES. 1999. *Presents findings of case study in a local context, examining family participation from multiple perspectives.* Call for price.
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- NATIONAL DIRECTORY OF ORGANIZATIONS SERVING PARENTS OF CHILDREN AND YOUTH WITH EMOTIONAL AND BEHAVIORAL DISORDERS, THIRD EDITION. 1993. *Includes 612 entries describing organizations that offer support, education, referral, advocacy, and other assistance to parents.* \$12.00.
- NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS CONFERENCE PROCEEDINGS. 1990. *Development of parent organizations, building coalitions, family support services, access to educational services, custody relinquishment, case management.* \$6.00.
- NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS (BOOKLET). 1991. *Designed for use in educating about children's mental health issues. Single copy: \$2.50. Five Copies: \$7.00.*
- ORGANIZATIONS FOR PARENTS OF CHILDREN WHO HAVE SERIOUS EMOTIONAL DISORDERS: REPORT OF A NATIONAL STUDY. 1991. *Study of 207 organizations for parents of children with serious emotional disorders.* \$4.00.
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- RESPITE CARE: A KEY INGREDIENT OF FAMILY SUPPORT. 1989 CONFERENCE PROCEEDINGS. *Starting respite programs, financing services* \$5.50.
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- STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT FINAL REPORT. 1990. *Evaluates the development of parent organizations in five states.* \$5.00.



# FOCAL POINT

THE DRIVING FORCE: THE INFLUENCE OF STATEWIDE FAMILY NETWORKS ON FAMILY SUPPORT & SYSTEMS OF CARE. 1994. *Highlights 1993 activities of 15 statewide family advocacy organizations.* \$9.00.

THERAPEUTIC CASE ADVOCACY TRAINERS' GUIDE: A FORMAT FOR TRAINING DIRECT SERVICE STAFF & ADMINISTRATORS. 1990. *Addresses interagency collaboration among professionals in task groups to establish comprehensive systems of care for children and their families.* \$5.75.

THERAPEUTIC CASE ADVOCACY WORKERS' HANDBOOK. 1990. *Companion to the Therapeutic Case Advocacy Trainers' Guide. Explains the Therapeutic Case Advocacy model, structure of task groups, group process issues, evaluations.* \$4.50.

WORKING TOGETHER FOR CHILDREN: AN ANNOTATED BIBLIOGRAPHY ABOUT FAMILY MEMBER PARTICIPATION IN CHILDREN'S MENTAL HEALTH POLICY-MAKING GROUPS. 1994. *Ideas for enhancing family member participation and conceptual models regarding increasing participation.* \$6.25.

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A COMPLETE LIST OF OTHER PUBLICATIONS AUTHORED BY RESEARCH AND TRAINING CENTER STAFF. *Lists journal articles, book chapters, monographs.* Free. Also available on the web: [www.rtc.pdx.edu/resource/puborder.htm](http://www.rtc.pdx.edu/resource/puborder.htm)

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