CAREGIVERS OF SERIOUSLY DISABLED CHILDREN AND THEIR RELATIONSHIP ISSUES WITH THE LABOR MARKET

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Abstract

There are significant social, physical and emotional burdens associated with the lives of caregivers of seriously disabled children (MacDonald & Callery, 2007; Wakabayashi & Donato, 2005). Caregiving for a disabled member of the family, particularly severely disabled children is frequently provided by women and often leads to isolation from society and interferes with the caregivers' opportunities to participate in the labor market. The challenge to facilitate support services to caregivers so employment is possible is a challenge to most societies and there are few totally successful remedies. Although there is some research linking the needs of caregivers of seriously disabled children and the labor market consequences for caregivers (Lilly, Laporte, & Coyte, 2007), the United Kingdom, Australia and the United States (Cass, 2006; Gray & Edwards, 2006; Heller, Miller, & Hsieh, 1999; Lilly et al., 2007) have published research in an attempt to study this emotionally charged dilemma. This paper reviews some of the more recent literature pertaining to the challenge of offering caregivers of seriously disabled children an opportunity to participate in the labor market.

Introduction - Caregivers

Caregiving is a crucial service in societies, often offered without pay, it preserves the health of disabled or aging citizens. State health systems would be unable to provide adequate coverage to the disabled without the caregiver contributions (Talley & Crews, 2007). Singer, Biegel, and Ethridge (2009) state, "Caregivers support family members who experience disabilities related to much physical and cognitive impairment that restrict normal functioning. These disabilities can first become evident at any time, ranging from birth, in the case of children born with some developmental disabilities, to advanced old age, in the case of family caregivers for relatives with dementia. In the United States and Canada, the family is now the main provider of long-term care, even for people with severe disabilities" (p. 98) As in most countries, the care of seriously disabled children most often falls to the parents or family of the child and reduces the use of institutional care for the child (Freedman & Boyer, 2000; MacDonald & Callery, 2007).

Caring for children with severe disabilities within the family has never been a social policy based on what is best for families, but based on the philosophy of "normalization" as being in the best interests of the child (Cummins, 2001). The care need of a disabled child is an emotionally charged issue for the family and the families are often considered crucial in this endeavor. The disabled individual, often in need of services to support physical needs, social integration and emotional well-being, frequently relies on the family for meeting most of their care needs. Most societies believe that these caregiving services are best delivered by the family (Cummins, 2001). However, families have changed significantly over the past generations and it is not as common that generations of families live in the same residence. This means there are often not multiple adults to relieve each other from the constant pressure of offering care to the disabled child. Families are smaller, there more single parent families and it is often more rare for there to be a non-parental adult in the same home (Cummins, 2001). Contemporary families are supported by a smaller number of adults, fewer older children to offer assistance, and often families survive in more complex social circumstances than in the past (Cummins, 2001).

In the past, parents often outlived their seriously disabled children; this is no longer the case. Individuals living with many different kinds of disabilities are living longer and better and this means caregivers are attending to the needs of the disabled for a growing portion of their lives (Mac Donald & Callery, 2007; Talley & Crews, 2007). While much of the research shows the quality of life for family is low (Cummins, 2001), this is also acknowledged as not always the case. The stress related to caregiving is related to the seriousness of the disability (Chan & Sigafoos, 2001; Cummins, 2007).

In the past, as is true today, caregivers were overwhelmingly women. However, historically women were not employed in the labor market to the same degree as today (Talley & Crews, 2007). Today, women are fully represented in the labor market but still take on the majority of the caregiving tasks and financial burden (Carmichael, Hulme, Sheppard, & Connel, 2008; Cass, 2006; Cummins, 2001; Edwards & Gray, 2009; Pavalko & Henderson, 2006; Talley & Crews, 2007; Wakabayashi & Donato, 2005). While societies have become more familiar with the nature of caregiving, they have not yet developed adequate solutions to aid with the lifespan, never-ending nature of the caregiving responsibilities for carers (MacDonald & Callery, 2009).

The nature of caregiving today is more complex as additional stresses and life experiences tax families (Chan & Sigafoos, 2001; Singer, et al., 2009; Talley & Crews, 2007). In addition, broad societal issues such as contributing to and being rewarded by the labor market, are often ignored as the female informal caregivers are not accounted for in the labor statistics because their work is unpaid and they are counted as not seeking employment or wishing to remain unemployed (Cass, 2006). However, issues of how contributions to the labor market are made can not be considered outside what society considers labor contributions. Whether the caregiving labor is considered may be based on if the labor is paid or unpaid, formal or informal and other societal boundaries. It is a complex equation because caregiving is often determined within the family system and the contribution is in danger of being minimized because the care, offered every day, every hour and taxes the physical, emotional, and social strengths of the entire family, is unclaimed and frequently invisible to most (Cass, 2006).

Historically, research has given most attention to caregivers as related to the social and psychological challenges and needs for caregivers (Talley & Crews, 2007). Recently, however, attention has been focused on the more inclusive concept of quality of living issues related to caregiving. This shift has resulted in some countries, like the United States, claiming that caregiving is a public health concern.

Consequences of caregiving

Individuals involved in the care of seriously disabled children are at risk of experiencing health problems (Talley & Crews, 2007). In addition, there is strong evidence that the work of caring for an ill or disabled family member has a substantial impact on health and well-being (MacDonald & Callery, 2007; Singer, et al., 2009). For example, Pavalko and Woodbury (2003) cite research that demonstrate caregivers consistently experience higher rates of depression than non-caregivers, although add that there is some question of whether this effect is due to the care work itself or the impact of having an ill or disabled family member. Studies examining the complex effects of care work on physical, emotional and social health of caregivers found that caregivers have more disease symptoms, physical limitations, and chronic conditions and poorer immune function.

In some situations, seriously disabled children who move into institutions from living at home often do so not because of a significant change in their health status, but because of the increasingly poor health of the caregivers (MacDonald & Callery, 2007; Talley & Crew, 2007). Some forms of physical stress for caregivers are suggested to be more detrimental to health than forms of psychological stress. Caregivers report not getting enough sleep, not participating in exercise, eating regular and nutritious meals and failing to seek medical attention for themselves resulting in clinical depression, isolation from social activities, and high stress and low quality of life (Cummins, 2001; MacDonald & Callery, 2007; Talley & Crews, 2007). If the caregiver is depressed, exhausted and lacks resilience, they may not leave their home and miss out on the social interactions causing a significant decrease in the quality of life (Talley & Crews, 2007).

These facts indicate that caregivers require supportive services for their caregiving tasks, but also supportive services to find quality of life and balance in their lives (Talley & Crews, 2007). Research suggests that if the caregiver is healthy, the person being cared for will experience much better care (Talley & Crews, 2007). Parents who are younger may experience a significant protective factor in the caregiving to a young child, despite the stresses and adjustments experienced to the family. However, in most countries, people are living longer, including those who are living with chronic illnesses and disabilities. As the seriously disabled child ages, the entire family system ages and this may call for additional forms of caregiving support services to meet the challenges of the aging family (Talley & Crews, 2007).

Cummins (2001), in a study on caregiver stress and quality of life reviews research based on 17 studies and finds that all but one of the studies discovered higher levels of stress or distress leaving little doubt that the care of seriously disabled individuals leads to low levels of subjective well-being for the family. The quality of life, or satisfaction with life as a whole, measured at a severely diminished level (Cummins, 2001). Cummins states the challenge with caregiving at home for a seriously disabled child is complex because of the three competing needs; the child, the State, and the family. There is little doubt that there are significant personal and social benefits for people with disability to be cared for by a healthy, loving and supportive family. Disabled children have a generally improved lifestyle and quality of care, certainly in comparison with conditions in some, if not most institutions. There is also no doubt that the economic benefits for governments are tremendous when the health care needs of their disabled children are met through unpaid labor. Governments have saved billions of their currency through the utilization of free care provided by families. But what is often forgotten or ignored in this equation is the cost to the families, most particularly the mother, who is most commonly the primary caregiver in such circumstances (2001).

There are, of course, many positive reasons why caregiving is socially supported and these include 1) the State's economic rewards, 2) not all families are overly stressed, and 3) there can be some significant emotional rewards derived from caregiving (Cummins, 2001). The economic rational is a strong incentive for family care in that when the availability of family caregiving exists, the State does not have to pay the expenditures for caring for the disabled person. This approach shifts the cost of care to the family but does so with little to no attention to the individual needs of the family or their individual or collective well-being (Cummins, 2001). Cummins (2001) questions the negative results of ignoring the multiple areas of caregiver stress and suggests that when families experience unrelieved stress related to caregiving, it negatively influences the quality of family life and well-being and can damage the care provided to the disabled individual.

Family care is good because it is better for the care recipient than institutional care. Moreover, it is consistent with professionals' views on the best provision of care. Relatively few families will be so stressed by the process that they will find the task impossible. However, again, notably absent from such sentiments is concern for the impact of caregiving on the care recipient's family (Cummins, 2001). It is recognized that under some conditions, where families have an abundance of social, emotional, and material resources, the stress of caregiving can be minimized. However, the fact that very few real-life families enjoy such positive conditions, it remains overwhelmingly questionable that home care is a positive experience for the family as a whole (Cummins, 2001).

Caregiver needs

As a result of the extra demands of caring for a child with disabilities, cargivers must rely on family support service through health and social organizations to provide assistance, education and relief, such as home care and respite to aid them with their caregiving roles (Damaini, Rosenbaum, Swinton, & Russell, 2004; Freedman & Boyer, 2000). Unlike professionals who provide similar care in institutions, parents may not receive regular breaks from care giving. As a result, parents, over time, experience health and social consequences related to care giving. Forms of relief, such as respite care, is one form of offering a short break from caregiving, and such relief is frequently cited as an unmet need by such parents (MaceDonald & Callery, 2007). States must develop a thoughtful and thorough approach to determining the services that best meet the needs of caregivers (Talley & Crews, 2007). What forms of interventions best support the health of the caregivers? Programs, services and interventions are needed that are shown to improve the life of caregivers.

Strengthening the capacity of families has become the emphasis of a number of programs designed to support the relatives and caregivers of the seriously disabled. The goals of supportive programs are to strengthen the capacity of families to care for the disabled as well as to improve the quality of life for caregivers (Heller, et al., 1999). The services offered often include;

- Respite care: Respite services can be provided in two distinct ways; formal caregiving, provided by nonprofit or for-profit agencies to give caregivers a short break from caregiving responsibilities. Informal respite care is care provided by relatives, family or friends who are not associated with any agency or organizational body to provide short term breaks to caregivers (Chan & Sigafoos, 2001; Damaini, et al. 2004).

- Counseling: Offered to individuals, groups or families, counseling offer often "stressed out" families an opportunity to deal with frustrations in an open and healthy manner. Counseling is also seen as a way to reduce potential health problems.
- Newsletters: Communication about opportunities and services as well as training and educational information can all be shared via newsletters. This service can be used to lessen isolation by giving notice to caregivers about resources offering assistance and support (Singer, et al., 2009).
- Family networking: Isolation adds to the burden of caregiving and often keeps families from sharing common problems and problem-solving techniques. Having opportunities for families to network with each other, via the internet or through face-to-face interactions, is shown to improve a sense of socialization and lessen the sense of isolation (Singer, et al., 2009)
- Training programs: Training programs offer support in many different ways and the training can teach coping strategies, behavioral management, or employment training. The most significant factors that influenced women returning to the workforce in Cass (2006) study was their participation in the labor market within the previous 5 years, their contact with a Jobs Education and Adviser, and their participation in a form of job training program.

These forms of support were shown to result in less family stress (Heller, et al., 1999) and to lead to an increase in satisfaction with services and support and fewer unmet service needs for family caregivers. When families are offering all of their time for caregiving, they are sacrificing other attention to other areas of their lives (Lilly, et al., 2007).

Lilly, et al., examined the impact of unpaid caregiving on caregivers' labor force participation and on their hours of labor market work. They found that individuals have a series of choices when faced with caregiving decisions. First, the individual or often the family must decide whether to accept the caregiving role. This decision is influenced by many emotional factors but also includes an economic decision. Next, the working individual, if they decide to take on caregiving responsibilities, must then determine whether to remain in the labor force and how many hours per week they will devote to unpaid caregiving. The caregiver family must examine their current economic state and perhaps their multiple roles in the labor force. Most often it is the woman who must negotiate the possibility of maintaining or sacrificing her employment status. The availability of other family members who may be able to take on caregiving duties may influence this decision, but often the decision includes how much unpaid versus paid employment can continue to support the needs of the family (Lilly et al., 2007).

Caregivers and work

An intensive literature review was initiated in English over the past 20 years by Lilly, Laporte, and Coyte (2007) to investigate the research that included search words such as at least one of "family caregiving," or "informal caregiving," or "unpaid caregiving," combined with at least one of "employment," or "labor supply," or "labor force." The studies revealed that the most common unpaid labor includes activity such as "personal care activities such as bathing, dressing, and feeding the care recipient; assisting with toileting, taking medication, and using medical devices; preparing meals and cleaning up; cleaning the house; doing the laundry; maintaining the house; shopping for groceries; taking the care recipient to medical appointments; and helping with paying household bills and banking" (Lilly et al., 2007; Singer, et al., 2009).

There results confirmed that those most likely to be involved in caregiving and absent form the labor market included; women, those in poor health, those who were older or nearing retirement age, those more involved in caregiving duties, immediate family member of the disabled recipient of care, those with more significant caregiving responsibility such as a highly degree of recipient needs, those with young children at home, those with lower income and those with lower levels of education (Lilly, et al., 2007). The issues regarding employment are, of course, very complex and may also be influenced by the financial entitlements societies offer caregivers and the total income of the family (Lilly, et al., 2007). Lilly, et al., conclude with the following analysis, "It would seem that both caregiving and labor force participation can be maintained when caregiving responsibilities are relatively small, as they are for the majority of unpaid caregivers. But when caregiving duties become heavy, caregivers are significantly less likely than noncaregivers to be employed" (2007, 676).

Balancing unpaid and paid work

There are questions regarding the reality of caregivers who attempt to attend to caregiving needs for a seriously disabled child and at the same time maintain employment; balancing unpaid and paid work. Caregiver/employed workers who must combine the two spheres of labor lead to two chief concerns. The first is whether combining paid employment and care work creates even greater strains on individuals than either of these roles on their own. Recent research has indicated that negative health effects of care work are generally reduced by other roles and that employment appears to be particularly beneficial for moderating the demands associated with care work. However, the demands of care work for ill or disabled family members remain substantial, and these demands may affect individuals, their families, and their workplaces.

Labor market issues

In Australia, as in most countries, most of the caregivers are the female family and friends of the person requiring the assistance (Gray & Edwards, 2009). While the informal care for the disabled and those with long-term health problems is of enormous economic and social value, there is no denying that the provision of this care has a negative impact on the labor market because it limits the supply of carers of working age who could contribute through their paid employment (Gray & Edwards, 2009).

The limitations for caregivers to be represented in the labor market are not likely to diminish. As women are increasingly represented in the labor market, the issue of informal caregiving will continue to be an important issue and influence the decision making of the family (Gray & Edwards, 2009; Pavalko & Henderson, 2006; Singer, et al., 2009). In the United States, Pavaloko and Henderson (2006) suggest that "roughly one in five adults between the ages of 35 and 64 is providing care to an ill or disabled family member either inside or outside the home" (p. 360).

There has been little research on exactly what determines a caregiver's inclusion into the labor market, and the research that does exist often compares the labor market opportunities of carers to those who are not involved in caregiving. Gray and Edwards (2009) examined this issue and attempt to estimate the factors associated with the labor force status of carers using data from a new survey of Australian carers. This study examined the estimated determinants of the labor force status of female carers, and included an analysis of unemployment and marginal attachment (i.e. people who want a job but are not actively looking for work or who are actively looking for work but are not available to start work) as a labor force state. The data was collected on 1002 cargivers based on the results of June 2006 of Carer Payment and/or Carer Allowance. The data was random and the results were examined based on the work of female carers in the labor market. Females were examined because the number of men carers of working age was so low (Gray & Edwards, 2009).

Gray and Edwards (2009) found that for caregivers, being involved in both paid and unpaid work could best be conceptualized as a "time allocation problem". Caregivers were faced with the challenge of allocating their time across work, social, physical and emotional needs as well as care-giving activities. In the model used by Gray and Edwards, the results indicated that care needs can be provided in a number of ways: entirely provided informally by family members, entirely purchased in the market (formal care) or by a combination of formal and informal care". Gray and Edwards determined that informal or formal care is determined upon the carers access to the labor market income (2009).

Furthermore, within the family context, family decisions about how economic needs were best addressed suggested that the caring is frequently accomplished by the family members with the lowest value of their alternative time use. Within the Gray & Edwards model, the value of alternative time use is the wage rate the person could earn in the market if employed and their likelihood of being able to find employment. As an alternative to the family informally providing the care, families also looked for care that could be purchased through the market and the higher the potential wage rate, the more likely that the person responsible for providing the care will purchase the needed care through the market (2009).

The results have important implications for the design of support services to caregivers, such as income support payments to carers, the market options for purchase of care, issues of respite and relief of caregiver stress, and the extent to which resources should be expended to attempt to help carers find employment (Gray & Edwards, 2009).

Carmichael and Charles (2003) used a related interpretation and noted that the time constraints of being involved in paid and unpaid labor could lead to the individual substituting unpaid caregiving work for paid work or, alternatively, the lack of financial incentive typically associated with informal caregiving may increase the incentive for the individual to undertake paid work.

Caring may also reduce the likelihood of carers being employed if employers are less willing to offer employment, or if employers offer lower wages to carers because of the potential impact of caring on their productivity in the labor market. This is a form of employment discrimination that pays a carer less because of the perceived potential negative impact upon productivity because of the time and emotional demands of caring or because caring can have an adverse impact upon the health of carers (Gray & Edwards, 2009).

The limited Australian evidence on the impact of having caring responsibilities on labor force status supports the conclusion that having caring responsibilities reduces the probability of employment (Gray & Edwards, 2009). Interestingly, they found that the major factors that are associated with lower rates of employment for female carers are having a low level of educational attainment, poor health of the carer, providing full-time care, caring for a child with a disability and not having people outside the household to provide support (2009). Care needs of a specific family providing care differed due to the intensity of care provided such as the disabling condition and caring role; household composition and demographic characteristics; support networks; family relationships; mental and physical health; educational attainment; and financial wellbeing (Gray & Edwards, 2009; Henz, 2006; Porterfield & McBride, 1997).

Carmichael et al., considers the impact that caring responsibilities have on women's employment. The research is based on a questionnaire and in-depth interviews with informal caregivers. The results suggest that carers' employment is affected by the duration of a caring episode, financial considerations, the needs of the person they care for, carers' beliefs about the compatibility of informal care and paid work, and employers' willingness to accommodate carers' needs. Overall, the research confirms that female informal carers continue to face difficulties when they try to combine employment and care in spite of recent policy initiatives designed to help them (2008).

In addition, caring needs within a family do not remain constant. Caring status can change for a number of reasons, including the death of the person being cared for, the requirement for institutional care, or a change of primary carer. But the number of people with informal caring responsibilities will continue to increase in coming decades and this caring can often lead to a withdrawal from the labor market and in many cases a reliance on governments for income support payments (Gray & Edwards, 2009).

Gray and Edwards propose that the fact that a large number of not-employed carers of working age expressed a desire to be in paid employment suggests that supporting such carers may be worthwhile and result in higher levels of social inclusion. Given that carers cited workplace flexibility as one of the barriers to finding a job (see Gray et al., 2008), encouraging increased workplace flexibility may provide opportunities for carers to be involved in the workforce. Suitable alternative care arrangements, the other major barrier to employment cited by carers, implies that appropriate and routinely available care arrangements would also help facilitate increased employment rates. Maintaining paid employment and attachment to the workforce are particularly important given that many carers, particularly those of working age, will not remain carers all their life (2009).

Forms of caregiver support

Cummins (2001) suggests there is a need to provide a balance between the advantages that caregivers provide the disabled and the emotional, physical and social costs borne by the family. MaCallion and Nickle (2005) state, "However, psychosocial interventions have the potential to alleviate these barriers and promote positive aging for persons with developmental disabilities" (p. 245). Caregiving is an activity with financial and social costs which extend beyond private and public boundaries and it is essential to examine how these costs are shared by pooling of resources or support between carers, families, communities and within society (Cass, 2006). Attention must be spent to the support needs of the carer and the family if the care provision if the desire is to meet the needs of the disabled child, economic needs of the state and at the same time offer the caregiver balance in their lives, maintaining a good quality of life (Chan & Sigafoos, 2001).

Family support services refer to a type of menu or grouping of both formal and informal services designed and created to promote the caregivers and caregiver families by promoting the benefits of caregiving and reducing the social costs. As the child grows and the needs change, so do the needs of the family caregivers (MacDonald & Calley, 2007). The chief goal of support for family caregivers is to enhance the quality of life for the caregiver and ultimately, the child receiving care (Chan & Sigaffos, 2001; Singer, et al., 2009).

Three areas that are addressed in the literature include; 1) employer policies, 2) a variety of respite services, and 3) formal market driven support services.

Employer Policies

There are many ways employers can play a role in the success of caregivers who attempt to balance paid and unpaid labor and studies show that policies such as family leave, flextime, and child care assistance are associated with better labor-market outcomes, work commitment, and other employment outcomes.

Demographic shifts mean that workers will increasingly face challenges of caring for ill or disabled family members. Workers in jobs that provide access to flexible hours, unpaid family leave, and paid sick or vacation days are more likely to remain employed and maintain work hours over a two-year period, but access to job benefits has little impact on women's distress. Although most policies do not provide additional benefits for employed caregivers than for other workers, unpaid family leave does increase their employment retention (Pavalko & Henderson, 2006).

In respect to paid employment for carers of working age, state governments often declare objectives to encourage and enable carers to remain in work and to help those carers who are unable, or do not want to combine paid work with caring, to return to work when their caring responsibilities cease. Even though these objectives reflect government recognition that caring responsibilities can constrain employment, the less explicit goal is one of moving more carers into employment. Sometimes this is done without assessing whether this is what they or the people they care for, actually want. Carmichael, et al., suggest that although the government recognizes the role of carers more than has previously been the case, there is ''disappointingly'' little discussion of carers' needs in policy formulation. Instead of receiving more incentives to move into or remain in paid employment, some carers might prefer to receive more financial support in order to either reduce their hours or take a temporary interruption from employment (2008).

Cass (2006) also investigates the risks of labor force withdrawal of carers in the Australian labor system. Cass recognizes that the vast contributions to society in caring for the seriously disabled child, is not rewarded with market wage or benefits of vacation time, time off, sick days, or the socialization or self-esteem associated with success in market labor (2006). Once out of the labor market, even for a specific time, returning to the labor market may hold special challenges due to the inability to compete with others applying for work who have not been removed from the labor scene (Cass, 2006). Ability to find employment may depend on the applicants' skills, training, experiences, education, geographic location, and ages and number of children (Gray, Qu, Renda & deVaus, 2003).

There is relatively little about whether workplace policies indeed ease this burden, and to date, what is known has been based on small, non-representative samples or employees from a single workplace (Pavalko & Henderson, 2006). The policy issues regarding any form of caregiver support are complex. Who is eligible for support services within the labor market and under what conditions?

Respite Care

Respite is not a new form of support for caregivers and serves as an invaluable service for people taking care of individuals that need constant attention (Chan & Sigafoos, 2001; MacDonald & Callery, 2007). Although caregivers often act selflessly in the caring of the disabled, the work inflicts an emotional, physical and social burden. Typically, however, the initial offer of respite can be met with caregiver of family ambivalence and providers of care may be hesitant to acknowledge that they require relief time. Often, especially if the carers are parents, they may believe that the desire of respite from their child means they are bad parents. At other times, the kind of respite being offered is not necessarily designed to meet the caregiver need, but is designed to be most convenient for the State (MacDonald & Callery, 2007; Starkey & Sarli, 1989). Respite care has been acknowledged as reducing caregiver burnout and stress and providing support, enhancing coping mechanisms, improving caregiver self-esteem, and enhancing family cohesion and adaptation (Chan & Sigafoos, 2001; Damaini, et al., 2004).

Providing full-time care is estimated to reduce the probability of being employed and increases the probability of not wanting to work. Importantly providing full-time care was also associated with a higher rate of wanting to work (unemployed or marginally attached). This suggests that additional regular respite care being available to carers is likely to result in a significant proportion of carers who are unemployed or marginally attached becoming employed (Gray & Edwards, 2009).

Some of the primary ways of offering respite support to cargivers of seriously disabled children are addressed by Starkey and Sarli (1989). These services include:

- Recruitment of Providers: Locating and encouraging individuals, families, organizations or other resources that can provide forms of respite for pay.
- Case Management: The maintenance of professional staff through an organization that work to facilitate supportive problem-solving for personal, family and community issues regarding the care of the seriously disabled child.
- Family Counseling: Provision of professional staff to meet with individuals, families or groups to empower and encourage empowerment and strength. Group counseling is particularly cost-effective and encourages mutual aid and support among caregivers and utilized when accommodations for the seriously disabled child are offered during the time spent meeting.

- Disabled Client Counseling: Provision of professional staff to develop and create educational, social and emotional support services using a variety of intervention methods. Provided within a day time treatment center, these services also provide respite to caregivers as an out-patient form of support.
- Family/Caregiver Training: Training to parent in behavior management techniques with the support of respite services.
- Case Identification (Outreach): Actively seeking parents and caregivers within the community to facilitate support services.
- Case Identification (Referral): Actively working within a network of contact and support services to assist caregivers in identifying available resources.
- Day/Evening Respite (Emergency): Services may provided with a foster or group home or within an institutional setting without an overnight stay until the emergency a response to the emergency is in place.
- Day/Evening Respite (Scheduled): Services may be provided within a foster or group home setting or within an institutional setting without an overnight stay to facilitate a planned short break for the caregiver.
- Overnight Respite (Emergency): Services may provided with a foster or group home or within an institutional setting with an overnight stay, until the emergency a response to the emergency is in place.
- Overnight Respite (Scheduled): Services may be provided within a foster or group home setting or within an institutional setting with an overnight stay to facilitate a planned short break for the caregiver.
- Home Support: A trained and employed individual who arrives at the home and offers specific health related services and training to the disabled child within the home.
- Homemaker Services: The assistance of a trained and employed individual who visits the home for predetermined hours and days within a week to assist or take on the chief responsibility of care, for instance for 3 days a week for 4 hours per day.
- Crisis Intervention: Respite care available in case of emergency along with a crisis contact and caregiver support, perhaps via telephone.
- Recreation/Socialization Activities: For-profit or non-profit organizations that offer daily outpatient respite for disabled children during the work day. The respite includes social outing and recreation activities and therapies by trained and employed personnel.

Buying formal services

There is a very strong sense of moral determination associated with whether caregivers provide the care to a disabled child or if they determine to purchase formal care. Beliefs about what is the right thing to do, sense of loyalty and the intrinsic rewards of caring are very important in decisions as to whether to provide informal care or purchase formal care (Gray & Edwards, 2009). But it is no longer taken for granted that mothers and daughters should be expected to sacrifice careers and other life goals to care for relatives with disabilities, even though such sacrifices are quite common when other care arrangements are not affordable or acceptable (Singer, et al., 2009).

One significant consequence of relying solely on informal caregiving is that it may seriously affect women's economic well-being. "In the short term, caregiving may compete with women's employment and create losses in working hours and earnings. Over time, these negative effects may accumulate and contribute to elderly women's disproportionately higher risk of living in poverty" (Wakabayashi & Donato, 2005, 467). Singer, et al., states "Family caregiving impacts employment in ways that create a need for community supports designed to reduce the number or work hours caregivers miss" (2009, 102).

In countries where there is increasing encouragement for maximum labor force participation, increasing access to formal care services is being identified as a possible option. Foster homes, group home, home services and other forms of supportive care are useful ways for caregivers to purchase the necessary services if they are able to afford them based on their participation in the labor market. States may also offer entitlements or financial compensation for portions or the whole of these forms of care through state contracts. Because those with the heaviest of caring commitments are the individuals most likely to not participate in or leave the labor market, a menu of formal services may allow for increased participation in the weekly hours of labor market work (Lilly et al., 2007).

Conclusion

The labor market is influenced by two significant trends, an increase in women participating in the labor market and the aging of the workforce. Workers and employers will continue to be challenged on how to facilitate opportunities for the large population of particularly women caregivers who are within working age range to balance the responsibilities of paid and unpaid labor (Pavalko & Henderson, 2006). There are well-documented personal costs associated with providing care to disabled children and there are significant short- and long-term public costs associated with this care. "Care work increases labor turnover for employers, and the increases in psychological distress may reduce productivity among those who remain employed. Workers who leave the labor force to provide care lose immediate access to the income and benefits of their jobs, and throughout the life course, labor-force exits have a significant impact on the basis for Social Security benefits (pensions), thus increasing the risk of income insecurity in later life" (Pavalko & Henderson, 2006).

Given the potential costs of caregiving to both workers and employers, do workplace policies that provide flexibility make a difference? Is the development of a menu of respite and supportive services enhance opportunities for caregivers to join the labor market without severe emotional penalty and loss of quality living? Are formal services offering short term support services available to offer service for pay? It is crucial that the dialogue of entry, training or retention within the labor market for caregivers include options to reduce the workload they already manage and assist them in maintaining their good health to the benefit of the child, the State and for themselves.

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SÚLYOSAN-HALMOZOTTAN FOGYATÉKOS EGYÉNEKET GONDOZÓK MUNKAVÁLLALÁSÁNAK KÉRDÉSEI

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Összefoglaló

A szakirodalmi forrásfeldolgozás a súlyosan-halmozottan fogyatékos egyéneket gondozók életét és munkaerő-piaci esélyeit mutatja be az USA, Kanada, Ausztrália és Nagy-Britannia területén.

Az elemzés szerint a fogyatékos személyek gondozásának kérdéskörében három szereplő sokszor ellentétes érdekei rajzolódnak ki: ezek maguk a fogyatékkal élők, másodszor az állam és végül a család. Ha a fogyatékkal élők érdekét nézzük, kétségtelen, hogy számukra – az esetek többségében – jobb szerető családi körülmények között élni, mint állami ellátó intézményekben. Az otthoni nevelés, gondozás előnyösebb az államnak is, hiszen költségmegtakarítást jelent számára a „fizetés nélküli" gondozó, és így nem kell plusz kapacitást (bentlakásos férőhelyet) fenntartania. A nevelést, gondozást ellátó személy általában családtagja, rokona, esetleg közeli ismerőse az ellátásra szorulónak. Ebben a relációban azonban gyakran maga a gondozó érdekeit hagyják figyelmen kívül: egyedül marad, nem kap segítséget, ráadásul munkájáért nem részesül anyagi elismerésben, kompenzációban, illetve az általa végzett gondozás miatt keletkezett többletköltségeit sem térítik meg. Mindez ellentétben áll azzal a ténnyel, miszerint a fogyatékkal élők számára az állami egészségügyi ellátó rendszer önmagában képtelen megfelelő ellátást biztosítani a családban gondozók tevékeny részvétele, segítsége nélkül. Ez tehát azt jelenti, hogy a legtöbb esetben nem az állami ellátórendszer, hanem a család látja el hosszú távon a fogyatékossággal élőt.

A fentiek alapján rendkívül fontos lenne az állam részéről a családban élő fogyatékos személyt gondozók jólétének biztosítása, azonban munkájuk jelentőségteljességének felismerése ellenére még mindig kevés az irányelv és a stratégia helyzetük megkönnyítésére, szükségleteik figyelembevételére. Sőt, a kizárólag családban fogyatékos személy ellátásával foglalkozó egyének nincsenek számontartva a munkaerő-statisztikákban, mivel „fizetés nélküli", „nem nyilvántartott munkatevékenységet" látnak el, így nem számítanak sem munkavállalónak, sem munkakeresőnek.

A tanulmány rávilágít arra is, hogy manapság sokkal összetettebb körülmények között történik a fogyatékosok nevelése, mint korábban. Figyelembe véve a feltételrendszer változásait elmondható, hogy a családrendszer nagymértékben megváltozott az elmúlt évtizedekben; ma már nem lakik együtt több generáció, akik segíthetnének a fogyatékos személy családban történő ellátásában, sőt, a jelenkori feltételek között sok esetben egyedülálló szülő gondoskodik a fogyatékkal élő személyről. Napjaink sajátosságai közé tartozik az is, hogy a fogyatékkal élők gyakran hosszabb ideig élnek, mint gondozóik, ami szintén prob-

lémát vet fel. Az azonban a korábbiakhoz képest sem változott, hogy az érintett családok ma is inkább elszigetelten élnek, valamint az a tény, hogy a gondozók többsége még mindig elsősorban a női nem képviselői közül kerül ki.

A munkaerő-piacot nagymértékben befolyásolja a nők növekvő számú munkavállalása és az elöregedő korfából is adódó, „idősebb korú" humán erőforrás. A munkáltatók folyamatos kihívásokkal néznek szembe abból a szempontból, hogy tudnak-e munkavállalási lehetőséget biztosítani az idősebb, a családban fogyatékos személy nevelését végzőknek. (Ilyen lehetőségek kínálkozhatnak a részmunkaidős vagy az atipikus foglalkoztatásban, az alternatív munkavégzésben.) Bár ezekben az esetekben a munkaadók a gondozást végző személyeket általában alacsonyabb bérért foglalkoztatják, részben arra az okra hivatkozva, hogy számukra a gondozói tevékenység gyakran tartós kimerültséget okoz, ami a munkakörükben ellátott feladataik során esetleg alacsonyabb produktivitást eredményezhet.

A gondozó szemszögéből a munkaerő-piacra való első belépés vagy reintegráció számos korlátba ütközik. A tanulmány bemutatja, mely körülmények befolyásolják a munkába állásukat: ezek között említhető a gondozási idő hossza, a család pénzügyi helyzete, a gondozott személy szükségletei, valamint az, hogy mennyire egyeztethető össze a családban gondozás és a munkaerő-piacon vállalt munka, illetve a munkáltatók foglalkoztatási hajlandósága. Az ellátók szerint további akadály a munkahelyi rugalmasság hiánya. Számos szerző utal rá, hogy a nevelő kevésbé versenyképes azokkal a munkavállalókkal szemben, akik nem szüneteltetik munkájukat (nincsenek gyakran és tartósan táppénzen, betegszabadságon, fizetés nélküli szabadságon – egyáltalán a munkájuktól távol), ráadásul a munkáltatók hozzáállását nézve sem gyakori, hogy szívesen alkalmaznak olyan munkavállalót, akinek gondozási feladatai is vannak, miután – a vélemények szerint – ez az elfoglaltság kihathat az egyén munkahelyi teljesítményére.

A szakirodalmi áttekintés felveti annak szükségességét, hogy egyensúly alakuljon ki a gondozók által nyújtott előnyök és az általuk vállalt érzelmi, fizikai, társadalmi ráfordítások között. Míg munkahelyi keretek között a dolgozók szabadságra tudnak menni, a családban fogyatékos személy gondozását végző ezt többnyire nem teheti meg. Megoldást jelentene a más, hasonló helyzetben lévő szülőkkel való kapcsolattartás, különböző konzultációkon, tréningeken való részvétel, a család többi tagja egy időre felmenthetné a gondozót a feladatai alól. Szintén segítség lenne olyan személy kiegészítő, ideiglenes igénybevétele, aki a konzultációk, a tréningek tartása mellett, szükség esetén nappali vagy éjszakai sürgősségi ügyeletet vállalna, a családban gondozót bizonyos ideig tehermentesítve, illetve folyamatosan vagy alkalmanként meglátogatná a családokat otthonukban, esetleg krízis-intervenciót biztosítana a problémával küzdők számára. Így a családban gondozónak nem kellene a teljes napot a fogyatékos gyermeke, családtagja ellátásával töltenie, ami az elszigeteltség és kétségbeesés miatt elvesztett önbecsülésének fokozatos visszanyerése mellett segíthetne a munkába állás lehetőségének megteremtésében is.

További javaslat a gondozók terhelésének csökkentése a munkáltatók által való hozzájárulás (alternatív munkavégzési rendszerek lehetősége, rugalmas hozzáállás és belátás) révén annak érdekében, hogy a családban fogyatékos személy ellátásának problémájával küzdő munkavállalóik egészségük megőrzése mellett nevelhessék, gondozhassák fogyatékos gyermeküket, rokonukat. Kutatások szerint a családban nevelők sokszor tragikus leterheltségük és gyakran kilátástalan helyzetük miatt nagyobb mértékben tapasztalnak problémákat saját egészségükben, könnyebben kapnak el betegségeket, amelyek hátterében stresszes életük és az ennek következtében legyengült immunrendszerük áll. A család-

ban gondozó egészségi állapota befolyásolja az általa biztosított ellátás minőségét. Ennek megfelelően fontos felismerni azt a tényt, hogy a családban gondozók részbeni tehermentesítése által előnyösebb helyzetbe kerülhetne az általa ellátott fogyatékkal élő személy, maga az állam és javulna a nevelők életminősége is.

Kulcsszavak: fogyatékkal élők, családban gondozás, munkavállalás