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Life Review with Families Who Care for Developmentally Disabled Members: A Model

Nancy P. Kropf, PhD
Roberta R. Greene, PhD

ABSTRACT. While adult caregiving has recently received greater attention, parents who continue to provide care for an adult child with a developmental disability have been an omitted group of care providers. In this article, life review is discussed as an interventive technique which can aid these parents with their late life caregiving responsibility. Six practice principles are derived for using life review techniques with these parents. Using an ecological framework, four case examples are included that demonstrate how life review can assist these parents with stress associated with the caregiving role.

Although adult caregiving recently has received great attention in the literature, researchers have focused little on parents who continue to perform a caregiving role into their aging years. As the population of older people increases and becomes more diverse, the number of families who will face the challenges of this caregiving situation also will increase. Because of age-related changes in both parents and adult children, these families may require additional social supports at a time when fewer supports are available.

Life review is a therapeutic technique that social workers have used extensively in assisting older individuals with life transitions. In this article, the authors discuss the use of life review as a psychotherapeutic intervention specifically with those older adults who

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care for adult children with developmental disabilities. Using an ecological perspective, the authors describe the stresses related to this caregiving situation and the coping strategies used by these families. Through case studies, the authors explore the use of life review as a means of enhancing families' adaptive capabilities.

THE LIFE REVIEW PROCESS

In a hallmark article, Butler (1963) proposed that life review is "a naturally, universal mental process" (p. 66) with great psychotherapeutic value. Since then, research and clinical studies have substantiated the view that life review therapy can be an effective means of evaluating the personal accomplishments and disappointments of a lifetime–those elements that are necessary to achieve an integrated sense of self (Greene, 1983; Kivnick, 1988; Sherman, 1991).

Although life review often is thought to occur more intensely in old age, it is a mechanism for re-evaluating all life stage transitions. According to Kivnick (1988), "The elderly person is involved in a struggle to bring feelings of integrity and acceptance into some kind of balance with realistic fears and desperation" (p. 64). The conflict is in balancing earlier tensions between generativity and stagnation, intimacy and isolation, and other life stages. Integrity is associated with psychosocial well-being at all stages, and stems from the opportunity for positive review or evaluation (Erikson et al., 1986; Sherman, 1991).

The process of life review at the final life transition is an attempt to balance syntonic and dystonic tendencies in a lifetime of psychosocial development. Erikson (1980) has suggested that the most potent factors of middle age include procreativity, creativity, and productivity. During this life stage, many parents work to nurture and socialize their children with the purpose of preparing the next generation. They expect that as their children mature, they will assume increasing responsibilities for themselves. In old age, these parents also expect to review and reconcile the care they provided earlier in life (Kivnick, 1988). However, elderly parents of developmentally disabled adult children instead may need to deal with the issue of "perpetual parenthood" (Jennings, 1987, p. 430). Life

review, then, can assist the older adult, and in some cases the adult child, in resolving or mitigating the conflicts of dependence and independence that are part of this extended caregiving situation.

Although life review may be considered an adaptive mechanism that helps individuals work through issues important to ego integrity, ego integrity also is intimately related to the complementarity between that person and his or her environment. The match between the family and its linkages to educational, health, economic, religious, and other institutions is a significant factor in the ego integrity of its individual members. The goodness-of-fit between an individual's needs and his or her environmental resources and support may determine the relative adaptive balance of families with members who are developmentally disabled (Germain, 1973). Therefore, therapeutic activities must address the person-and-environment fit.

A framework for understanding connections between people and their environment is Bronfenbrenner's (1989) concentric circle model (Figure 1). He has posited that an individual is embedded within a multilevel environmental context from membership within a family (microsystem) to a more diffuse cultural system (macrosystem). The first level, the microsystem, identifies the role relationship between individuals, such as the connections between members of a family. The second level, the mesosystem, comprises the linkages between microsystems, for example the connections between a family and the school system. The exosystem, the third level, involves linkages between two levels, one of which does not include the developing person. Relationships between systems at this level are, for example, local governmental agencies and group homes for developmentally disabled people in communities. The fourth level, the macrosystem level, contains overarching patterns within a broad social context. This level of the model includes relationship patterns, values, and norms, that are affected by variations among ethnic and other cultural groups (for example, gay and lesbian groups, people with physical disabilities, and so forth). Additionally, the macrosystem contains formalized interaction patterns involving laws, policies, and resource allocation. Life review is an interventive method that can help older parents integrate past experiences and stresses on any of these levels.

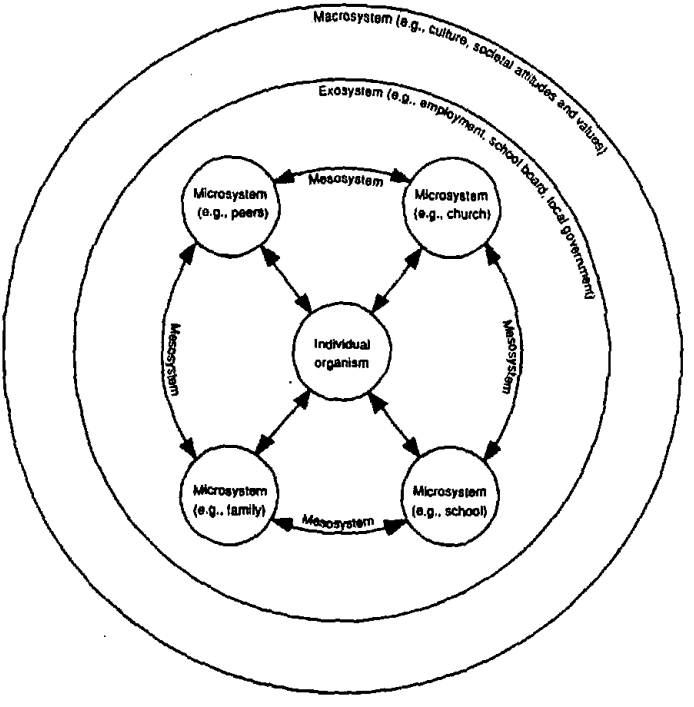

Figure 1. The levels of the ecological system with permission from Hefferman, J. Shuttlesworth, J. and Ambroseno, R. Social Work and Social Welfare. St. Paul: West Publishing, 1988.

PARENTS OF A DEVELOPMENTALLY DISABLED CHILD

Caregiver Stress. The literature is replete with studies describing the stress experienced by parents who are raising a disabled child (Crnic et al., 1983; Quine & Pahl, 1985). Caregiving stress associated with this role comes in chronic and episodic forms. Chronic stress is a function of the continuous responsibility of caring for a disabled person, a responsibility that involves, for example, finding respite providers or financing specialized services and equipment (Roth, 1982; Tavormina et al., 1981; Wikler, 1981). Episodic, or transitional, stress is manifest at certain developmental periods. For example, especially stressful periods are when the disabled child

should have started to walk, talk, enter a school system, graduate, and reach independence (Wikler, 1986; Wikler et al., 1981). These are times when parents are acutely reminded of the delayed developmental mastery of their disabled child.

Older parents who continue caring for a developmentally disabled adult child also experience stress. These perpetual parents face multiple demands in their effort to continue in the caregiving role (Jennings, 1987). Parents report worries and fears about their child's future (Gold et al., 1987; Mulcahey, 1986), problems in finding and accessing needed services (Caserta et al., 1987; Janicki et al., 1986), and a lack of respite care options (Joyce et al., 1983; Lutzer & Brubaker, 1988).

Differences in the aging process between the developmentally disabled adult child and the parent affects the caregiving relationship. For example, the onset of Alzheimer's Disease for the general population typically occurs after age 60 years. However, people with Down's syndrome, the most prevalent form of genetic retardation, may display symptoms of Alzheimer's disease at much younger ages (Miniszek, 1983; Lott & Lai, 1982). Thus, older parents may need to provide additional care for a disabled child or consider residential options at a time when they too are experiencing age-related changes.

Another effect on the caregiving relationship in families who care for developmentally disabled members is the absence of adult rituals that symbolize autonomy and independence. Most parents in these families never see a developmentally disabled child marry, graduate from college, start a career or family. Parents do not benefit from the external symbols that mark changes in their caregiving role. Rituals also have relevance for continuing cultural practices and patterns within a family. For example, a son with mental retardation may not be able to master the religious instruction necessary to participate in a bar mitzvah. His parents miss the opportunity to celebrate his induction into an adult role in the synagogue, as well be a part of passing a cultural tradition to the next generation.

Coping Strategies. Although families with a developmentally disabled member face multiple sources of stress, the majority of families manage to cope with their situation. Coping has been related to both personal coping and social supports (Schilling et al., 1984).

Parents tend to use particular coping techniques to deal with the stress of caring for a disabled child. For example, they may compare their circumstances with others who are less fortunate, they may perceive they have more control over their life, and they may believe that the experience has positive effects (Friedrich et al., 1985; Schilling & Schinke, 1983). Use of social support, another form of coping, has the effect of buffering stressful effects of caregiving. Parents of developmentally disabled offspring derive support from multiple sources including other family members, friends, neighbors, and formalized services and institutions (Friedrich et al., 1985; Quine & Pahl, 1985).

The aging process of parents and adult child, however, may have a negative effect on the coping strategies of these families. For example, the aging process can limit both personal coping mechanisms and available social support. Even later in life, caregiving remains a central role for these parents (Seltzer & Krauss, 1989). Therefore, the perception of uncompleted caregiving can have a negative impact on the developmental process of older parents (Brunn, 1985). Their own aging, changes within the family system, and the changing needs of their adult child may alter their existing supports.

LIFE REVIEW WITH OLDER PARENTS

Parents of adult children with developmental disabilities have encountered both personal and environmental stress in performing their caregiving role. As a therapeutic approach aimed at assisting with life transitions occurring during this stage of development, life review can ameliorate dysfunctional processes.

In the ecological perspective, competence is achieved through a goodness-of-fit balance between individuals and their environment. Using the ecological perspective as a framework, the authors have identified six life review principles in working with older parents. These six principles provide a structure for interviewing parents about the transactions which have transpired between their families and the larger environment over the life course. In the life review process, the associated meanings of these events should be explored by the practitioner. Alternative meanings that promote a sense of

competence with the parents also need to be investigated. The first four principles are associated with the assessment aspect of the therapeutic process; the last two, with the treatment aspect. These principles are as follows:

1. Identify points of stress
2. Assess coping styles, including age-related changes
3. Understand the family history of involvement with environmental supports
4. Determine the extent of the person-environment fit
5. Enhance social supports of all family members
6. Help resolve issues of personal integrity as those issues relate to all family members.

The following case examples illustrate each of these principles of the life review process. Social workers can use these principles with this segment of older adults to help deal with the problems faced on the different ecological levels (microsystem to macrosystem).

Microsystem. At the microsystem level, families with a developmentally disabled adult may experience stress because of the chronic caregiving responsibilities undertaken by the caregivers in these families. Time for building relationships between family members and other sources of support may be hampered by the caregiving responsibilities. Consider the following case example of the Anders family.

> Mrs. Anders is the 72-year-old mother of a daughter with mental retardation, Sharon, who is 33-years-old. Sharon is independent in her activities of daily living (that is, dressing, bathing, and feeding) and she is able to assume some responsibilities around the house such as running the vacuum, carrying groceries, and washing dishes. Sharon and her mother share a warm relationship and spend most of their free time together at home watching television or shopping at the mall.
>
> Mr. Anders died about 6 years ago. One older daughter in the family lives in an adjacent community with her husband and two teen-aged daughters. Unfortunately, Sharon has always been extremely jealous of her nieces, which causes problems when the family is together. Sharon is also jealous of her

mother's other friendships, and demands her attention by speaking loudly, pulling on her sleeves and beginning to cry. Although Mrs. Anders has always enjoyed cooking and socializing, she recently eliminated entertaining to appease Sharon.

An issue of importance to Mrs. Anders is the relationships she shares with different members of her family. She has indicated that she really enjoys Sharon's company: "She's all I have left at home since my husband died." However, Mrs. Anders laments her limited relationship with her other daughter's family and lost friendships. Mrs. Anders has expressed that "I wish I could have been more available for my older daughter when she was growing up. I feel like I sacrificed that relationship to keep Sharon at home. I'm sad that I haven't had the time to spoil my granddaughters, and spend more time with my friends in the church auxiliary."

Two assessment principles–identify points of stress and assess coping styles–could be applied to the Anders case study. In the example, Mrs. Anders discussed her relationship to the oldest daughter. She expressed both sadness and guilt about the course of the relationship, that she was unavailable to the older daughter during her development, and that she currently has a limited connection to this daughter. Mrs. Anders also expressed sorrow over the lack of opportunities to entertain in the home, which was an activity that she enjoyed tremendously. In an attempt to cope with Sharon's disruptive social behavior, the Anders family tried to manage the tension of Sharon's jealousies by restricting family interactions. While in the short-term tension was contained, the lasting effect was alienation between the family and their social supports.

During life review with Mrs. Anders, the practitioner can help balance the losses and gains of her caregiving role. Although Mrs. Anders has made sacrifices to provide care to Sharon, it appears that Sharon's presence in the household might have assisted Mrs. Anders to cope with the death of her husband. Sharon provides companionship to her mother and assists in activities of household maintenance. The life review process can help Mrs. Anders appreciate the emotional and tangible support which she derives from her daughter Sharon.

Life review with Mrs. Anders also can help to identify present

and future caregiving strategies and evaluate potential benefits. On a positive note, currently there are more caregiving resources to help Mrs. Anders than in previous decades. Services to adults with mental retardation now include vocational, recreational, and respite programs. Involvement in these programs can benefit Sharon by increasing her social opportunities and skill development. Mrs. Anders also can benefit from these programs since she will have time apart from her daughter to develop and reconnect with both friends and family members. Although Mrs. Anders cannot retrieve lost opportunities, she can be encouraged to use resources to create satisfying relationships at this life stage.

Mesosystem. Because a family has a disabled member, parents may need to advocate and connect with numerous other systems. A continuous responsibility for caregiving families is achieving linkages with medical, educational, and vocational programs. However, other systems that could assist these families may be avoided because of the stigma attached to having a disabled member, an issue that is exemplified in the following case.

> Mrs. Hawkins is a 66-year-old mother of a son with multiple disabilities. Anthony, who is 39-years-old, has mental retardation, a seizure disorder, and cerebral palsy, which affects his gross motor and verbal skills. Recently, Anthony has started to use a wheelchair because of decreased physical strength. He also suffers from excessive salivation and drools severely. His disposition is very pleasant and he enjoys company.
>
> Mrs. Hawkins describes her feelings of isolation in raising her son. She recounted her own hurt and anger on numerous occasions when neighbors would have birthday parties and not invite Anthony. Since Anthony is sociable and enjoys community activities, Mrs. Hawkins would take him to the circus or zoo. Often she would hear people comment about "that poor mother having to raise a cripple." On the occasions when Anthony had a seizure in public, it would be evident that people were shocked and disgusted.
>
> Since Anthony has become non-ambulatory, he has been forced to withdraw from his day program because the transportation service could not accommodate wheelchairs. Mrs.

Hawkins's arthritis now prohibits her from transporting Anthony without assistance. The few friends who used to help with Anthony have aged and cannot provide the support they had in the past. Although Mrs. Hawkins and her son would still enjoy going on outings together, they spend most of the time at home watching television.

Two principles–understand environmental supports available to the family and determine the degree of environmental fit–could be applied to this case study. Both Anthony's and Mrs. Hawkins' aging process have necessitated an increased need for support while their support system has decreased. Although Anthony is outgoing and sociable, he has been avoided by others because of the severity of his physical conditions.

The purpose of the assessment process is to evaluate the degree of the person-and-environmental fit. In the Hawkins case, the family needed diverse resources to manage Anthony's developmental and physical disabilities. In life review, Mrs. Hawkins can be assisted in identifying and reconciling the tremendous energy she has invested in the family to meet Anthony's physical and social needs for many years. As part of this process, Mrs. Hawkins may re-explore her feelings surrounding past situations where Anthony has been alienated, ridiculed, or scorned due to his disability. Life review in the Hawkins case should attend to the present functioning status as well. For example, Anthony's mother can also be reassured that the current transportation problem did not mean she was an inadequate care provider for her son.

As both mother and son age, other sources of support will need to be identified. Because the physical conditions of both Anthony and Mrs. Hawkins probably will continue to deteriorate, the social worker should prompt the family to discuss future caregiving plans, for example the possibility of living in a group home in the community. As part of the life review process, the practitioner can help identify resources and explore the meaning the family attaches to the change in the caregiving situation.

Exosystem. Local government decisions about resource allocation and zoning ordinances affects the availability of number and sites of group homes in the community. Such an exosystem issue

directly affects caregiving families because communities that support few group homes provide limited residential options for people with developmental disabilities. The effects of these limited options are evident in the following case study.

> Mr. and Mrs. Folkes are the parents of a daughter, Ella, who is 24-years-old and has mild mental retardation. Mr. Folkes has recently retired from his job as plant supervisor. The Folkes are in their early sixties, are currently financially stable, and are fairly healthy. They have been looking forward to retirement and planning how they will spend their "golden years" together traveling and enjoying outings with their many friends in the community.
>
> Ella also has been looking forward to her parents' retirement. Although the three family members get along reasonably well, Ella also feels that she wants additional independence. She speaks excitedly about moving into a group home or a semi-independent living arrangement.
>
> Unfortunately, the Folkes discovered that the waiting list for residential placements in their community is about 2 years long. The Folkes considered relocating to another community, but that would mean severing ties to their friends, extended family, and church congregation. Mr. and Mrs. Folkes are concerned about "not getting any younger" and the possibility that they will not be able to fulfill their dreams later. The loss of income through retirement also would make it difficult to pay for Ella's continued care and would strain the household budget. Ella is upset and confused about why she cannot fulfill her dream of adult independence from her family.

The treatment principle that is derived from the life review process is to enhance available supports. Mr. and Mrs. Folkes appear to have a functioning social support system–they have ties to their church and friends, and they have adequate financial resources. Ella, however, has expressed her desire to establish her own support network by moving out of the family household. The unavailability of residential options in the community, though, may negatively affect the supports of this family. The parents are eager to enjoy

their retirement years together, but continued caregiving responsibility and expenses could limit their activities.

The life review process can help the Folkes focus on past and present disappointments about lack of community resources. The social worker can help the family become aware of the cumulative effect of small disappointments, such as the unavailability of respite care and the lack of recreation options for disabled people. All members of the family will need assistance in dealing with disappointments such as the loss of the "retirement dream" for the parents and an "independent living dream" for Ella. Problem solving with the family also can help family members identify ways of partializing their wants and desires. For example, the family might be able to identify an adult foster care home in the area that would provide periodic short-term respite care for Ella so the parents could travel and Ella could live independently with others similar in age.

Macrosystem. A major political advancement for developmentally disabled people has been the transition from a segregated to an integrated work environment. The Rehabilitation Act of 1973 prioritized services for people with severe disabilities including affirmative action in hiring practices. In 1986, the Rehabilitation Act (P.L. 99-506) was amended to provide funding for supported employment programs (Hughes & Wehman, 1992). These programs identify employment sites for people with disabilities and provide employment training and on-the-job support. The following case study describes how increased vocational options for a developmentally disabled daughter influenced one family.

> The Jackson's are a retired couple who live in the same household as their 32-year-old daughter Marie, who has mental retardation. For the past 10 years, Marie has attended a vocational workshop where she has consistently produced outstanding work. About 2 months ago, a social worker at the workshop suggested to the Jackson's that Marie participate in a supported employment program that was being created through the workshop. A number of community businesses were interested in hiring people with disabilities and a job coach was available to train the new workers in their job responsibilities. The job coach had identified a small bakery as a possible placement for Marie.

> The Jackson's have expressed mixed feelings about the placement. The family has identified some positive aspects about the work in the bakery. For example, Marie is excited about making her own money (the job pays minimum wage) and the Jackson's admit the money could help pay household expenses. Marie also is excited that she will have the opportunity to learn how to ride the bus to work; part of her pre-employment training involves learning how to use public transportation. However, the family has voiced concerns about this placement. Mrs. Jackson discussed the possibility that Marie might fail in the position. She recalled when she had "tried to have Marie attend a special Girl Scout troop. Marie couldn't stand it and we were asked to not bring her back anymore." Mr. Jackson, a recent retiree, questioned whether Marie would be physically able to perform the work. "Working 7 hours a day takes a lot out of you. Marie's only a little thing, you know." Both of the parents commented that it would be hard to give up their family Saturday shopping trips, because Marie's job would require her to work Saturday mornings.

The life review treatment principle that can be applied in this case study is to promote the personal integrity of all family members. In providing treatment to this family, the practitioner needs to help family members learn to differentiate between past and present experiences, as well as learn how to reorganize family activities. The parents need to identify how the current employment situation differs from situations that have failed in the past. In addition to reviewing past failures, the practitioner should help the family review Marie's successes, such as her outstanding record in her sheltered workshop. Although Marie is involved in a supported employment program, she will encounter problems at the work site. The family needs to be educated more fully about the steps they should take if a placement does not progress well. In addition, the family can discuss alternative ways of spending time together to replace the loss of their weekly shopping trip.

In this case example, legislative changes for people with disabilities have increased the vocational options for Marie. However, family members have expressed ambivalent feelings about the

bakery placement. The parents have expressed their fears about the job, including the possibility of failure or the work being too strenuous. These issues appear to be connected to such past experiences as with the Girl Scout troop. Additionally, Marie's job has threatened the family shopping ritual, which is a source of enjoyment for all members.

SUMMARY

The case studies presented in this article support the perspective taken in earlier research that examines person-environment fit (Kahana & Kiyak, 1980; Kahana, Liang, & Felton, 1980). These examples suggest that competence, autonomy, and a sense of control over the environment are important factors in well-being and integrity in older adults. For example, Parmelee and Lawton (1990) demonstrated the substantial positive impact of minor increments in control of personal activities and social contacts, as well as the negative effects of loss of such control.

As a consequence of the extended caregiving relationship, parents who care for adults with developmental disabilities experience stress in multilevels of functioning that is often accompanied by a loss of control. Practitioners can use life review, a therapeutic technique that helps older clients with life transitions, with these caregivers. Life review can assist these parents gain an enhanced sense of control over their lives by integrating their disappointments and successes, factors that affect their perceptions about the future.

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