

Appendix

Essay - The Lost Generation
by Nancy Breitenbach

Sample Outreach Materials

- Demonstration sites
- From the sites

Tear Sheets

- Reading resources
- Environmental modifications
- Some common terms and acronyms
- Model carer support group
- National associations & organizations

Note to Readers: These appendices have been abridged since some of the original matter was dated and some was not saved in electronic format. Copies of the original appendices can be obtained from The NFCSP Project, Richardson 280, 135 Western Avenue, University at Albany, Albany, NY 12222.

The Lost Generation

By Nancy Breitenbach¹

In every country where people with developmental and psychiatric disabilities are enjoying a longer lifespan, this new phenomenon is generating a number of consequences:

- a certain perplexity among professionals with regard to the aging process itself, since service providers working with people who are disabled have had little experience with older adults;

- a progressive realization that services designed for younger people may not be adequate or appropriate for older individuals;

- a growing concern with the type and quality of services offered to elderly citizens in general, brought to light especially when integration into services for the aged is suggested for older people with mental or physical disabilities.

These issues are essentially related to the field of organized services. Greater longevity of people with developmental disability has also spotlighted other situations, in particular that of elderly caregivers (primarily mothers) who, after providing care for up to twice the normal childraising cycle, continue to provide it on a daily basis. Women who are great-grandmothers are still responsible for "children" they brought into the world shortly after World War II. Moreover, they expect to carry on until they drop.

Planning for the future of these caregivers as well as that of their offspring is a growing concern in a number of countries, where the needs expressed may be influenced

by cultural factors. But these variations are secondary to some universal issues. Despite the fact that often they have ensured their child's survival singlehandedly (perhaps because they have assumed this task singlehandedly), elderly caregivers and the middle-aged adults with developmental disability who have remained with them at home, have been largely forgotten. Only recently have we begun to rediscover what the lives of those who belong to this "Lost Generation" are like.

Early awareness of the problem goes back to the 80's, when several American articles on elderly caregivers were published and the film "Best Boy" won an Oscar. In Europe, I first described in 1989 the inextricable psychological dilemmas of parents who, after providing years of affection and home care to an adult with a developmental disability, find themselves faced with the prospect of residential placement. Jacques Rio, in his longterm study of the parallel aging process in employees of a sheltered workshop employees and their parents, also referred to deepset parental resistance, suggesting that some elderly caregivers were compromising their offspring's future by not accepting residential placement when offered.

Since then, other studies have come out and a French video tape on the subject has been produced.

An urgent concern

This growing interest is becoming an urgent concern because the

Lost Generation is fast running out of time. Each year makes it harder and harder for elderly parents to cope. Each year probably makes it harder and harder for their adult offspring to find appropriate services or adapt to a new lifestyle. The everpresent specter of an aged caregiver's sudden disappearance makes it necessary to plan now for the imminent future. And yet, if and when approached with offers of support, these families express ambivalent if not negative attitudes towards what social services have to offer.

From observing behaviors to understanding them

The challenges faced by elderly caregivers and their coping strategies can vary considerably. There appear to be a number of basic human responses which crop up consistently, regardless of the country or the culture where researchers have sought to make contact with the Lost Generation. Diane Serneels, for instance, has described different levels of parental behavior in terms of active and passive response: those who overtly seek solutions; those who think about the future but can't bear to talk about it though this may be necessary for their plans to materialize; and those who totally avoid the issue.

Such responses are important to recognize. However we must dig a bit deeper, if we want to help caregivers take concrete action, if we hope to defuse unconstructive reactions. Practitioners need to concern themselves not only with

¹ Nancy Breitenbach is Head of Programs for Disabled Persons at the Fondation De France, in Paris, France. She is a native born American who has been involved with disability activities for over twenty years and has been instrumental in developing an awareness as to the concerns of aging families in France. She has lectured and been involved in numerous activities in the United States. The *Lost Generation* was originally presented at the 1995 New York City Mini-White House Conference on Aging and Developmental Disabilities.

how elderly caregivers act, but with the motivations behind their actions. Policy-makers need more than figures on how many families avoid future planning. In order to implement effective policies, they need to know what has caused, and continues to cause, the particular attitudes adopted by the members of the Lost Generation.

Why have these families gone underground? Why do elderly caregivers find it so difficult to let go before the situation degenerates? What prevents them from ensuring against crisis placement by designing alternatives in a timely manner?

To find out, we need to go back in time.

The visible tip and the rest of an iceberg

Until recently, the caregiver problem which caught the attention of social services and advocacy associations, has been that of unmet demands for children and young adults with disabilities as expressed by their parents. These militants tend to be educated people who know how support systems work and have insisted on accessing available services or getting new ones created. In response to their repeated requests, public agencies have tended to increase the number and size of standardized services, aimed at those who already know the ropes.²

In contrast most elderly

² For example, every year in France brings new and glossier sheltered workshops and group homes, including a small but growing number of special retirement homes for older people with developmental and chronic psychiatric disabilities. But few have been able to obtain this type of placement. Those who gained admission 10-20 years earlier age in place, rather than give up their place to someone else. Moreover, access to specialized retirement homes is generally offered to individuals who have been clients of the service network for a number of years and whose new needs, due to age, require adapted services.

caregivers, whose career in disability began before the advocacy movement got off the ground, have rarely benefited from it. They have not kept up with the System as it has evolved over the past 30 years. They may lack the education necessary to understand how it works, or the confidence needed to knock on the door. Thus those who did not gain early entry into the network, or who have remained on the fringes, have considerable trouble getting in at the end of their lifetime. They and their offspring have never been at the right place at the right time.

This situation of "haves" and "have nots" has finally revealed the numerous and acute problems confronting older caregivers who, throughout their lifetimes, have been on the outside of the service network, looking in, and who tend to remain there. Those who have asked but never received, may have had no choice in the matter. But others appear to hold back, deliberately remaining silent. So the problem is not simply one of short supply. It's also a question of non-demand.

Ambivalent attitudes

Apparently a significant number of elderly caregivers are unaware of contemporary support opportunities. But their attitudes towards services are just as important in determining their behavior, for example those who do not feel right about requesting services, those who do not want them, and those who can't quite make up their minds.

Elderly caregivers may have very mixed feelings about their future and that of their adult child. A number of older parents formulate frank requests for services and then back off at the last minute. Others hedge their bets, calculating how long their strength will hold out, assuming that they can send their dependant child to a good residential service at any time. Some elderly

caregivers push their ambivalence to great lengths, for instance parents who have pioneered the creation of advocacy associations and residential homes for other peoples' children, but have insisted on keeping their own adult son or daughter at home.

Ambivalent attitudes are testimony to caregivers' internal conflicts, conscious and unconscious, about what could or should be done for their offspring, and what is nevertheless best for themselves. Separation is not necessarily their ideal.

Familiar environments, intertwined relationships and interdependence

When given the choice, most older caregivers prefer in fact to keep the disabled adult within the family environment. Diane Serneels' work shows that passive responses were present in 50% of the families interviewed, despite the fact that age and frailty were gaining on them all. This may say something about their perception of service provision and their ability to plan ahead. But it also says a great deal about the strength of family ties.

The lifetimes which elderly caregivers and their dependant children spend together may mean that they have become locked into set relationships, leaving little room for growth or exterior investment for any of the parties involved. Despite their restrictive aspects, these set relationships provide security.

Families who have survived the birth and infancy of an individual with a developmental disability, and developed the strategies for living which have allowed them to function without a break for years and years, have also developed the art of self-maintenance. They don't let each other go that easily. However cramped it may be, any nest occupied for an entire generation or more is hard to leave.

Moreover, the relationship may have evolved in such a way that letting go becomes extremely complicated.

Just as the shape of the nuclear family (father, mother, children) has evolved in many countries, families which have consolidated around an individual with developmental disability, have probably modified the standard configuration. The classical scheme of adults who provide and dependants who receive, has gradually grown into something else which is not always easy to define. For a number of years the person with a disability leaned on the caregiver who was able. In general this continues to be the case. But with time, the balance between strengths and weaknesses in each member of the family is likely to have shifted. At some point in time, the grown son or daughter has become more than a child.

Whether or not they head single-parent families, mothers remain the primary caregivers. Their longterm relationship with the disabled adult sitting at the kitchen table may have turned into something resembling that of an old couple: two people who rely on each other for company, each providing someone to talk to, someone with whom meals and activities can be shared on a regular basis. They are "odd couples", experiencing together the aging process (old age on the one hand, middle age on the other). Such dyads are particularly visible when a widowed mother finds herself alone with her middle-aged son. What woman wants to be widowed a second time?

Some elderly parents' identities are still tied up in the satisfying rôle of nurturer, but increasing age can bring about rôle confusion. Frail parents may find themselves physically less capable than their "dependant", in which case the family hierarchy becomes blurred. Rôle reversal may occur if the

dependent individual turns out to be the breadwinner³, especially if he/she knows it.

Some isolated caregivers may even require their offspring's presence in order to keep going. Having the person there everyday provides a reason for living, emotional support, social interaction, even indispensable household assistance if the adult child helps with arduous tasks or shopping. It is even suspected that in some cases, yet to be numbered, the "dependent" person becomes a caregiver in his/her own right, providing personal care to an elderly parent who cannot function alone either.

In another scheme, intense personal attachment, concentrated on only a few individuals over many years, may generate relationships reminiscent of the life-threatening ties joining Siamese twins.

To sum up, complex family relationships can result in a more or less advanced state of mutual dependence. Outsiders may judge these situations as being less than ideal. But no matter how problematic or tenuous these strategies for living may appear to others, they have proven to be functional within the given family ecology.

Each party involved, parent and child, has something important to lose if the tight-knit structure is

³ It is important to remember that the Lost Generation is largely comprised of retirees, whose set income may have lost ground because of inflation. Widows who never pursued careers beyond that of wife and mother, may be living at the subsistence level since their allotments are based on what their husband earned decades earlier (a significant proportion of the people living under the poverty line are elderly women). In such cases, the disabled person's contribution is essential to the overall budget. Thus the caregiver becomes financially dependant on the person cared for, and he/she may plunge into a state of destitution if ever this income disappears.

threatened. The sudden disappearance of one member or the other, due to death or brutal decisions made by third parties, can be a devastating experience. Awkward or aggressive attempts to pull apart the intricate ties may make the knots draw even tighter. If the family unit is sliced open like a Gordian knot, only shreds remain.

The challenge, then, is to discover where the ties lie, to recognize exactly what they hold together, and to find out how to ease the way open.

Fundamental distrust due to past experience

Another level of reticence, best defined as cultural and historical, can add to elderly caregivers' apprehensions.

The Lost Generation is a cultural group in itself. It is represented not only by elderly caregivers tucked away in rural areas and working class neighborhoods, but also by caregivers living in homes where people sit on Louis XIV chairs. What characterizes this group, beyond their age-group and the presence of a disabled person in the home, are memories of a certain era and a particular set of references.

Most elderly caregivers are not in touch with contemporary channels of information concerning disability. They actively resist the idea of placement because of a fundamental distrust of social services, having assimilated and retained the predominant ideas of their culture and/or generation, when:

- the presence of a child with mental retardation probably meant a stain on the family, someone to be kept out of the public eye;

- religious affiliation may have meant specific attitudes towards the disabled child, who represented an Innocent Lamb to be cherished or a Cross to bear;

- living conditions in special institutions of 50 or 60 years ago were rather poor, meaning that less than perfect children were better off (if not more likely to survive) if discreetly guarded at home. Parents who lived through the Nazi era learned particularly well not to trust loved ones to social services.

- parents may have paid dearly for contacts with social services in the early years of special education, when professionals' attachment to certain theories made them quick to denigrate or dismiss;

- or caregivers may have tried to obtain services and been told too often that their child was still on the waiting list (the ultimate irony comes when they are told after 20 years of requesting services that their adult child has become too old to adjust to a new lifestyle). Longterm discouragement and scepticism have set in;

- and in any case, expectations for the disabled person's lifespan were short when the child was growing up so planning for the future has probably always appeared absurd.

The Lost Generation has also probably retained value systems which are out of sync with modern times, not to speak of contemporary bureaucratic techniques. Unlike the "Me Generation" of the 80's which looks out for Number 1, unlike the baby-boom generation whose vision of the world is determined by their experience of the prosperous 1960s-1970s, this generation lived through the Great Depression and several world conflicts.

Having grown up themselves and raised their children during an age when the values of family, devotion, self-reliance and frugality were considered supremely valid, their positive self-image may continue to require respect for these same values. Inviting elderly caregivers to surrender their offspring to strangers who "know

better" and to accept public "charity", can mean asking them to abandon their values as worthless and to consider their years of commitment and self-sacrifice as wasted effort.

The fact that professionals are not aware of demanding that elderly caregivers give up the ideals which have given meaning to their entire lives, the fact that attitudes with regard to disability and the quality of services have generally improved, does not reduce older carers' deepest convictions. The historical attitudes and impressions they absorbed 40-50 years earlier still carry enormous weight. The past experienced by the Lost Generation continues to determine the present.

Conclusion

When considering the challenges confronting elderly caregivers, we should remember that we have challenges of our own to meet. We need to:

1) Learn to recognize and deal with the characteristic responses of older caregivers, when significant changes in lifestyle are proposed:

- those who actively seek or await solutions saying, "What took you so long?"
- those who plead, "Not just yet."
- and those, unconvinced that what we have to offer is any better than what they already have, who answer, "Not on your life."

2) Learn to think in terms of human ecosystems rather than individuals, and to acknowledge the needs of all those who have managed to function together for so long.

3) Conceive of and provide responses which meet these various needs: flexible services which structure positive transitions, but also approach techniques which

take into account the fact that whether caregiver or recipient of care, older persons find it difficult adapting to new, unfamiliar situations.

In other words, when reaching out to the Lost Generation, we need to care as much for the elderly caregivers' feelings and well-being, as we care for the older adults with a developmental disability.

Bibliography:

BEST BOY, video tape directed by Ira Wohl

Breitenbach, Nancy, "Le placement tardif des adultes handicapés vieillissants", READAPTATION, N° 362, Juillet-Août 1989

Rio, Jacques, "Le vieillissement des parents: évolutions démographiques et problématiques de relais à l'échelle d'un CAT (Période 1983-1990)", GERSE/Ateliers Denis-Cordonnier, Juin 1991

Serneels, Diane, "Older families with a mentally retarded son or daughter: the Belgian situation and recommendations for service delivery", unpublished paper presented at the European Course on Mental Retardation, Heel, Netherlands, October 5th, 1994

Van Walleghem, Marcel, "Families with an elderly mentally handicapped child: results of a qualitative study in Flanders (Belgium)", FAMILY NEEDS AND FAMILY SUPPORT IN MENTAL RETARDATION: An International Perspective, Ed M.K. Haveman & W.H.E. Buntinx, SWIHC International Symposium on Family Needs and Family Support in Mental Retardation, Maastricht, Netherlands, 1993 (pp 73-80)

WHITE HAIR, GREY HAIR, video tape directed by Jean-Marc Faure, produced by the Fondation de France, Paris. English subtitled version: 26", copyright 1994

*Nancy Breitenbach
September, 1995*

©

Reading Resources

Aging and Developmental Disabilities - Issues and Approaches. M.P. Janicki & H.M. Wisniewski (Eds.). Baltimore: Paul H. Brookes (1985).

Building the Future - Planning and Community Development in Aging and Developmental Disabilities. M.P. Janicki (Ed.). Albany: New York State Office of Mental Retardation and Developmental Disabilities (1993).

Casebook of Integration Experiences - Program Ideas in Aging and Developmental Disabilities. M.P. Janicki (Ed.). Albany: New York State Office of Mental Retardation and Developmental Disabilities (1993).

Developmental Disabilities and Alzheimer's Disease . . . What You Should Know. Arlington, Texas: The Arc (1995).

Facts About Adult Children with Developmental Disabilities and Their Families. Washington: American Association of Retired Persons

It's Time for a Change- A Guide to Match-up Homesharing As a Residential Option for Persons with Mental Retardation & Developmental Disabilities. LePore, P. Albany: New York State Office for the Aging (1995).

Life Course Perspectives on Adulthood and Old Age. M.M. Seltzer, M.W. Krauss & M. P. Janicki (Eds.). Washington: American Association on Mental Retardation (1994).

Meeting the Needs and Challenges of At-Risk Two-Generation, Elderly Families. Arlington, Texas: The Arc - A National Organization on Mental Retardation (1994).

Practice Guidelines for the Clinical Assessment and Care Management of Alzheimer and Other Dementia among Adults with Mental Retardation. Washington: American Association on Mental Retardation (1995).

The Elderly Caregiver - Caring for Adults with Developmental Disabilities. K.A. Roberto (Ed.). Newbury Park, CA: SAGE Publications (1993).

The Wit to Win - How to Integrate Older Adults with Developmental Disabilities into Community Aging Programs. P. LePore & M. Janicki. Albany: New York State Office for the Aging (1993).

Videos

White Hair, Grey Hair - For information contact Ms. Nancy Breitenbach, Head of Programs for the Disabled, Fondation de France, 40, avenue Hoche, 75008 Paris, France

When People with Developmental Disabilities Grow Old - For information contact, NYS Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, New York