

**HELPING THEM REST IN PEACE:
CONFRONTING THE HIDDEN CRISIS
FACING AGING PARENTS OF DISABLED
CHILDREN¹**

Luana Olivas

Over the past fifty years, the parents of developmentally disabled children have increasingly opted to care for their children at home, assuming full responsibility for providing the companionship and supervision that might otherwise have been provided in a state-sponsored institution. Today, many of these parents are now elderly and confronting the daunting challenge of planning for their disabled adult child's future. In this Note, Luana Olivas examines the painful choices facing these family caregivers as they try to navigate between two massive social service systems to find assistance for themselves and their children. Factors such as long waiting lists, rigid policies requiring parents to accept either more or less help than they desire, and poor communication between the parents and service providers all contribute to the failure of both the aging and the disability service

Luana Olivas is Administrative Editor 2002–2003, Member 2001–2002, The Elder Law Journal; J.D. 2003, University of Illinois, Urbana-Champaign; B.A. in Government 1998, Harvard University.

The author dedicates this note to her family, whose experience inspired this topic and whose strength inspires much more.

1. The title of this Note reflects the subject of a U.S. Senate Committee on Aging hearing entitled *Can We Rest in Peace? Anxiety of Elderly Parents Caring for Disabled Baby Boomers: Testimony Before the S. Spec. Comm. on Aging*, F.D.C.H. CONG. TEST., 105th Cong. Sept. 18, 1998 [hereinafter *Can We Rest in Peace?*], at 1998 WL 664476.

systems to address the needs of this population. Ms. Olivas concludes that more research is necessary to dispel the misconceptions on both sides of the divide and to provide solutions resulting in the most efficient and appropriate use of state welfare funds. By helping these parents plan for their children's long-term care, policy makers and service providers may ease the trauma of this transition for the disabled children, while acknowledging and respecting the wishes and sacrifices of their parents.

I. Introduction

A frantic phone call informs a developmental disability office that a disabled adult needs a place to live immediately because his parent just died. This news is troubling, but not unexpected. Such phone calls in the disability services community are frequent enough to have earned a label as the "Friday afternoon phone call."² Aging parents caring for their developmentally disabled³ adult children struggle with anxiety over how their child's needs will be met when they can no longer care for the child due to poor health or death.⁴ Growth of the nation's aging population and the increased life expectancy of disabled individuals have made it increasingly common to find a situation in which lack of planning and

2. CLAIRE LAVIN & KENNETH J. DOKA, OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES 122 (John Hendricks ed., 1999); Joan B. Wood, *Planning for the Transfer of Care: Social and Psychological Issues*, in THE ELDERLY CAREGIVER: CARING FOR ADULTS WITH DEVELOPMENTAL DISABILITIES 95, 106 (Karen A. Roberto ed., 1993) [hereinafter THE ELDERLY CAREGIVER].

3. The term "developmental disability" refers to a severe or chronic disability which is (1) attributable to a mental or physical impairment or combination thereof; (2) manifested before the person attains age twenty-two; (3) likely to continue indefinitely; (4) resulting in substantial functional limitations in major life activities; and (5) reflective of the person's need for a combination of care, treatment, or other services which are of life-long or extended duration. LAVIN & DOKA, *supra* note 2, at 21. Some studies or statements cited in this Note, although they relate to the topic in general, pertain to specific subsets of this category such as mental retardation. When this is the case, the specific category is noted.

4. Alan V. Kaufman et al., *Permanency Planning by Older Parents Who Care for Adult Children with Mental Retardation*, 29 MENTAL RETARDATION 293, 293 (1991) (noting also that aging is among the most common stress factors of caregivers); *Can We Rest in Peace?*, *supra* note 1, at <http://www.nami.org/cgi-bin/printfy.cgi?/update/981102233743.html> (testimony of Margaret Stout, executive director of the National Alliance for the Mentally Ill, testifying that the "most profound . . . concern is what will happen to their disabled children in the event that they become unable to adequately care for them").

inadequate resources create an uncertain and often undesirable future for aging parents and their disabled adult children.⁵

This matter's urgency is a function of both the severity of the crisis for those individuals affected by it and its increased prevalence. The "crisis" occurs when the disabled child's caregiver is dead or dying, leaving the child likely to be shuttled to a new living situation with people who are strangers to the child or to a long-term care services "slot" that may or may not be suited to the child's needs.⁶ Population trends contribute to the increased number of individuals who potentially face such a crisis. Among these trends is the prevalence of persons with developmental disabilities in the United States who live with family caregivers.⁷ Another trend is that the disabled now also have an increased life expectancy,⁸ and frequently outlive their family caregivers.⁹

The resulting increase in both duration and intensity of a parental caregiver's role makes it necessary for most parents to draw upon the formal support services that the aging and disability service systems are meant to provide.¹⁰ This increased demand for support services has been unanticipated by federal, state, and local agencies.¹¹ Consequently, "it is not an exaggeration . . . that many family caregivers must die before the disabled relative . . . receives appropriate residential and community services from the state system."¹² Even in less extreme cases, it is still only a crisis that causes some individuals to receive the services they need.¹³ Meeting this crisis strains families

5. See, e.g., Phillip McCallion & Sheldon S. Tobin, *Social Workers' Perceptions of Older Parents Caring at Home for Sons and Daughters with Developmental Disabilities*, 33 MENTAL RETARDATION 153, 154 (1995) (citing the increase in this population, lack of knowledge about their specific needs, and the lack of outreach to those not known to the system).

6. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 664474 (statement of Lorraine Sheehan, chairperson of The Arc's Governmental Affairs Committee).

7. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

8. *Id.*

9. *Id.*

10. See generally *id.* (citing relevant population trends and how these have "stimulated a growing need for more services and supports").

11. *Id.*

12. *Id.*

13. *Id.* at 1998 WL 664474 (statement of Lorraine Sheehan, chairperson of The Arc's Governmental Affairs Committee).

and available service systems.¹⁴ The most expensive level of care within both the aging and disability service systems occurs when a caregiving parent dies or becomes severely ill or incapacitated, and no plan for the child's continued care exists.¹⁵ Therefore, the systems literally cannot afford to ignore this growing need for support prior to crisis situations.¹⁶

Expansive government and local entities and programs committed to aiding the aging and disabled population do exist. They tend, however, to focus on aging and disability separately,¹⁷ rarely sharing their resources and often competing against each other for public resources.¹⁸ Thus, aging parents seeking services for themselves and their disabled child have to navigate, often unsuccessfully, between two massive systems to meet their family's unique needs.¹⁹ This problem requires that these divergent systems coalesce to form an innovative and multilateral approach to the crisis facing disabled adults and their families at both the policy and service levels.

The aging and disability systems, and the policies and programs that fund them, are complex. Rather than provide a comprehensive description and analysis of both structures, this Note focuses on some of the major obstacles to planning and providing for the long-term care of disabled children that the existing systems present. These barriers include lack of awareness among the support services systems of the needs, characteristics, or even existence of the aging parental caregiver population. Upon overcoming this lack of awareness, aging

14. *Can We Rest in Peace?*, *supra* note 1, at <http://www.senate.gov/~aging/f8jg.htm> (statement of Diane Coughlin, Director of Developmental Disabilities Administration, Maryland).

15. Katharine S. Hacker, Philip McCallion & Matthew P. Janicki, *Outreach and Assistance Using Area Agencies on Aging*, in *COMMUNITY SUPPORTS FOR AGING ADULTS WITH LIFELONG DISABILITIES* 439, 440 (Matthew P. Janicki & Edward F. Ansello eds., 2000).

16. In Illinois, for example, a short time prior to 1997, nearly five million dollars were budgeted for emergency placement of 120 developmentally disabled people, with the amount "including building facilities and long-term funding for care." Darlene Gavron Stevens, *'Who Will Take Care of Ray?': Elderly Parents of Disabled Adults Face the Inevitable*, *CHI. TRIB.*, Jan. 10, 1997, available at 1997 WL 3509612.

17. LAVIN & DOKA, *supra* note 2, at 89.

18. *Id.* at 95. This competition, in turn, inhibits cooperation between both systems. *Id.*

19. See Hacker et al., *supra* note 15, at 440 (indicating that older caregivers have become the "lost generation" within the services field and the failure to address their needs reflects conflicting views on whether the aging or developmental disability system is responsible for that failure).

parents must still face systems that, due to the inadequacy or rigidity of available resources, are unprepared and perhaps unwilling to help them plan for when they can no longer care for their disabled child. Part II of this Note describes the size and nature of this population and the primary systems from which they might derive support. Part III illustrates some of the barriers parents face in obtaining the support they need to care for their child as they age and in planning for the child's care when the parents can no longer provide it themselves. Finally, Part IV describes ways in which aging parents might obtain greater access to more appropriate support from a broader range of resources.

II. Background

A. The Population

There is little comprehensive research on parental caregivers of older developmentally disabled adults,²⁰ but population trends and estimated figures indicate that the aging and disabled population living with family caregivers is significant and will continue to grow.²¹ Developmentally disabled individuals are those who, due to mental or physical impairments, experience substantial functional limitations with major life activities, creating a long-term or lifelong need for care, medical treatment, and other services.²² In 1996, sixty percent of the 3.17 million people with developmental disabilities in the United States were receiving residential care from family caregivers.²³ This number is higher for the mentally retarded²⁴ population, eighty percent of which live with or under the supervision of their respective

20. Cf. Kaufman et al., *supra* note 4, at 294 (describing the dearth of research on permanency planning for parents of the mentally retarded).

21. See *infra* notes 26–29 and accompanying text.

22. LAVIN & DOKA, *supra* note 2, at 21. The services “needed by [the disabled] and their caregivers with advancing age . . . include programs, work and retirement options, caregiver support, environmental modifications, housing, and legal and financial assistance.” *Id.* at 89.

23. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago). “This . . . is five times the numbers served by the formal residential care system.” *Id.*

24. “The term *mental retardation* is the official term approved for use by The Arc . . .” Rick Berkobien & Sharon Davis, *Coalitions as Forces of Change and Support*, in COMMUNITY SUPPORTS FOR AGING ADULTS WITH LIFELONG DISABILITIES, *supra* note 15, at 109, 110 n.1. The Arc is an organization with 1,000 chapters across the United States that provides and advocates for services to individuals with intellectual disabilities and their families. *Id.* at 113.

families.²⁵ Moreover, as of 1998, nearly half a million individuals with mental retardation and related developmental disabilities who lived at home did so with caregivers who were sixty years of age or older.²⁶ This number stands to increase given the preference towards home-based family care for disabled children²⁷ and the increased life expectancy of disabled individuals.²⁸ Currently, there are an estimated 526,000 adults age sixty and older with mental retardation and other developmental disabilities.²⁹ That number will double to 1,065,000 by 2030 when all of the post-World War II “baby boomers,” born between 1946 and 1964, will reach their sixties.³⁰

Presently, an aging society coupled with the increased longevity of developmentally disabled people is stretching the limits of the aging and disability service systems.³¹ This reality puts policy makers “on a direct collision course as hundreds of thousands of adults with severe disabilities—who have for years been cared for by parents in their own homes—begin seeking housing and community supports from already overburdened public programs.”³² This population of families comprised of elderly or aging parents of adult disabled children are considered “part of a ‘hidden crisis’ expected to come to a head in 20 to 30 years.”³³

25. LAVIN & DOKA, *supra* note 2, at 40; Dr. Marsha Seltzer, Lecture on Aging Parents of Children with Mental Retardation, Lecture to Dartmouth College Developmental Disabilities Class, at <http://iml.dartmouth.edu/~william/iidd/html/ageparen.html> (last visited Aug. 24, 2002).

26. OLDER AMERICANS ACT AMENDMENTS OF 1999, S. REP. NO. 106-399 (1999).

27. See DAVID L. BRADDOCK, *THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES* 16 (5th ed. 1998); Kaufman et al., *supra* note 4, at 293. Although there is no requirement that parents act as caregivers, many jurisdictions recognize a parental duty to support adult disabled children who cannot care for themselves. See Dan R. Price, *Child Support for Adult Disabled Children: New Texas Legislation*, 22 ST. MARY'S L.J. 877, 881 n.15 (1991) (citing Noralyn O. Harlow, Annotation, *Postmajority Disability as Reviving Parental Duty to Support Child*, 48 A.L.R. 4TH 919 (1986)).

28. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

29. Tamar Heller & Alan Factor, *Older Adults with Mental Retardation and Their Aging Family Caregivers*, at <http://www.uic.edu/orgs/rrtcamr/OlderAdults.html>.

30. *Id.*

31. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

32. *Id.* at <http://www.nami.org/cgi-bin/printfvl.cgi?/update/981102233743.html> (statement of Margaret Stout, Executive Director of the National Alliance for the Mentally Ill).

33. Associated Press, *Aging Parents of Disabled Children Face Tough Choices* (May 17, 2000), at <http://www.healthcentral.com/News/NewsFullText.cfm?ID=53095&storytype=APNews> (last visited Aug. 24, 2002).

B. Deinstitutionalization Trend

The increase in the population and longevity of disabled individuals, combined with a deinstitutionalization trend, makes future planning for disabled children living at home even more pressing for their families.³⁴ Segregated residential institutions were the dominant model of publicly funded programs for the disabled.³⁵ The conditions in these institutions, however, came to be associated with a “cruel and oppressive period in which people with mental retardation were segregated in institutions, sterilized, and treated inhumanely.”³⁶ Landmark litigation and legislation during the 1970s marked the judicial and legislative push towards deinstitutionalization.³⁷ The early 1980s were the first time that states began closing institutions in significant numbers.³⁸ Since then, there has been roughly a sixty percent reduction in the number of residents in public institutions.³⁹ The population of individuals residing in institutions has decreased markedly and steadily each of the past thirty years.⁴⁰ Institutional phase-downs and closures have been accompanied by a growing emphasis on supported community living for individuals with developmental disabilities.⁴¹ Whereas before, families were pressured to “put their children away” from birth,⁴² they are now expected to be substantially involved in their care, if not directly responsible for it. This shift in care arrangements will translate into an expansion of social services prompted in part by an emphasis on providing support focusing on family needs as opposed to institutional needs.⁴³

34. McCallion & Tobin, *supra* note 5, at 153.

35. See BRADDOCK, *supra* note 27, at 16.

36. *Id.*

37. *Id.* at 8–9. Braddock also presents representative cases that resulted in states’ requirements to develop alternatives to institutions. *Id.* at 9. For instance, *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971), articulated a right of residents in state mental institutions to live in the “least restrictive environment,” and *Horacek v. Exon*, 357 F. Supp. 71 (D. Neb. 1973) and *Homeward Bound v. Hisson*, 963 F.2d 1352 (10th Cir. 1992), interpreted “least restrictive environment” as including community placements. BRADDOCK, *supra* note 27, at 16. Also, *New York State Arc v. Carey* included discussion of Eighth Amendment cruel and unusual punishment when defining this term for institutional residents. BRADDOCK, *supra* note 27, at 16.

38. BRADDOCK, *supra* note 27, at 9.

39. *Id.* at 26. Numbers declined from approximately 150,000 to 60,000 residents. *Id.*

40. *Id.* at 16; LAVIN & DOKA, *supra* note 2, at 19.

41. BRADDOCK, *supra* note 27, at 9.

42. Stevens, *supra* note 16.

43. BRADDOCK, *supra* note 27, at 17.

C. Overview of the Aging and Developmental Disabilities Systems

As they age, parents caring and planning for a developmentally disabled child will develop a need for the long-term care services offered by the aging and disability service systems.⁴⁴ Such planning includes “future residential, legal, and financial arrangements in addition to health care, vocational . . . activities, and [other] community supports.”⁴⁵ Although families and individuals privately cover some of the cost for these services, the financial drain is such that federal and state government sponsored programs are relied upon heavily.⁴⁶ Because of the distinct services each system offers, both have a pivotal role in determining how families cope with a disabled child as the caregiving parents age.⁴⁷ Meeting the needs of the aging disabled and their families will require coordination between the aging and disability service systems.⁴⁸ Thus, a basic overview of both systems, and how government funding affects their structures, is useful when identifying their shortcomings in meeting the needs of the disabled and their aging parents.

For the aging population, a system of federal as well as state and local agencies and organizations,⁴⁹ including a “variety of community services provider agencies,” provide support.⁵⁰ Most of the funding, however, comes from the federal level under the Older Americans Act of 1965.⁵¹ This funding is distributed by the Administration on Aging to federal agencies for the aging and state units, with states then distributing it to local Area Agencies on Aging (AAA) and local service

44. See Karen A. Roberto, *Family Caregivers of Aging Adults with Disabilities: A Review of the Caregiving Literature*, in *THE ELDERLY CAREGIVER*, *supra* note 2, at 3, 15 (“Families use[] more services when they report[] being less able to provide care for their aging members themselves.”); see also *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago) (noting that the extended duration of need for long-term care will “directly impact[] on the finite capacities of service delivery systems”).

45. Heller & Factor, *supra* note 29.

46. Symposium, *Addressing Long Waits for Home and Community-Based Care Through Medicaid and the ADA*, 45 ST. LOUIS U. L.J. 117, 119 (2001) [hereinafter Symposium].

47. See Berkobien & Davis, *supra* note 24, at 111 (suggesting “coalition building to achieve coordination of aging and developmental disabilities services and supports” as an approach to meeting the problems confronting “two-generation older families”).

48. See *id.* at 109.

49. *Id.* at 111.

50. *Id.*

51. *Id.*

providers.⁵² State and local governments also fund aging programs at their respective levels.⁵³ This system provides social services generally intended to maintain independence in the social, economic, and functional skills of the elderly.⁵⁴

The developmental disabilities system is comprised of public and private agencies that “plan, coordinate, administer, offer, or finance services” for developmentally disabled individuals.⁵⁵ The system’s services are generally centered on rehabilitation, vocational training, or special education.⁵⁶ Most funding comes from the respective state governments or private resources, with many states relying on federal funds for residential, day, and support services.⁵⁷ These federal funds for the mental retardation and developmentally disabled service systems are made available to states through the Medicaid program.⁵⁸

The federal Medicare and Medicaid programs heavily finance both systems. Medicare, a federal health insurance program, is a source of support for both the elderly and the disabled.⁵⁹ It is not, however, “fundamentally a long-term care program,”⁶⁰ and thus, it is not one that aging parents can rely upon for long-term support. Medicaid fills the “gap” in long-term care that Medicare leaves uncovered.⁶¹ Medicaid is a federal need-based program operating in large part at the state level and generally benefits the aged, blind, or disabled.⁶² It is used as a primary method of funding long-term care services because Medicare only pays for a limited amount of such care.⁶³ Although the disabled child might not start out being eligible for Medicaid’s need-based benefits, families who independently ar-

52. *Id.*

53. *Id.*

54. LAVIN & DOKA, *supra* note 2, at 91.

55. Berkobien & Davis, *supra* note 24, at 111.

56. LAVIN & DOKA, *supra* note 2, at 91.

57. Berkobien & Davis, *supra* note 24, at 111.

58. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

59. LAWRENCE A. FROLIK & MELISSA C. BROWN, ADVISING THE ELDERLY OR DISABLED CLIENT ¶ 9.1, at 9-2 (1992).

60. Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate” Requirements and the Independent Living Model of Long-Term Care*, 27 AM. J.L. & MED. 17, 25 (2001).

61. Robert L. Kane et al., *Variation in State Spending for Long-Term Care: Factors Associated with More Balanced Systems*, 23 J. HEALTH POL. POL’Y & L. 363, 366 (1998).

62. FROLIK & BROWN, *supra* note 59, ¶ 10.1, at 10-2.

63. *Id.* at 10-3.

range for home-based care risk depleting their assets down to the eligibility requirements. Regardless of income levels, individuals also become eligible when their medical expenses exceed their income.⁶⁴ These families must then turn to the Medicaid system for long-term care services.⁶⁵

To finance long-term care for the disabled, states receive Medicaid reimbursements from the federal government and use them to sustain state institutions qualifying as Intermediate Care Facilities for the Mentally Retarded (ICF/MR).⁶⁶ Medicaid funds also finance a "wide array of community services and supports" through the Home and Community-Based Services (HCBS) waiver program.⁶⁷ These waivers are special funds intended to help an elderly or disabled person live at home or in a community setting rather than in an institutional setting.⁶⁸ Under these waiver programs, states can use Medicaid funding to provide services not otherwise available to Medicaid recipients such as case management, homemaker services, home health aides, personal care, adult day health, habilitation, and respite care.⁶⁹ States apply for a specific number of waiver slots. To receive such waivers, states must assure that the cost of providing these services is less than the per capita cost of providing institutional services to the beneficiaries.⁷⁰ Medicaid, then, is "the principal catalyst of system expansion," with seventy-one percent of "public resources for the nation's mental retardation and developmental disability service system" associated with the ICF/MR or HCBS programs.⁷¹

64. See LAWRENCE A. FROLIK & MELISSA C. BROWN, ADVISING THE ELDERLY OR DISABLED CLIENT ¶ 10.1, at 10-4 (Supp. 1999).

65. See Batavia, *supra* note 60, at 18. "Due to the substantial financial burden . . . many of these individuals impoverish themselves until they spend down sufficient assets to become Medicaid-eligible." *Id.*

66. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

67. *Id.*

68. FROLIK & BROWN, *supra* note 64, ¶ 10.3[4], at S10-10 (citing 42 C.F.R. § 440.180).

69. *Id.*

70. Symposium, *supra* note 46, at 125. The waivers are only available for those who would otherwise be institutionalized, and one requirement for receiving the waiver is that "the state will spend less per capita than without the waiver." *Id.*

71. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

D. Legislative and Policy Initiatives Targeting Aging Parental Caregivers

Certain policy initiatives indicate that aiding aging family caregivers is moving to the forefront of the aging and disability policy agendas.⁷² In 1999, for example, an amendment to the Older Americans Act established the National Family Caregiver Support Program (NFCSP).⁷³ Among those targeted for benefits in this program were grandparents and relative caregivers over age sixty caring for disabled individuals aged eighteen or younger.⁷⁴ State service providers receiving the federal funds were required to make resources known to caregivers, facilitate access to services, train and assist caregivers in solving problems, and provide services to complement at-home care.⁷⁵ Moreover, the statute requires that states give priority to older individuals providing care to persons with developmental disabilities.⁷⁶ The NFCSP was part of a multifaceted federal long-term care initiative unveiled in 1999 by then President Clinton.⁷⁷ The proposal was significant because it highlighted the prominent role of families in providing long-term care for disabled family members. It also revealed a lack of awareness among these families that programs otherwise perceived as a source of support, such as Medicare, would not cover most of their long-term care needs.⁷⁸ A year earlier, the Senate Aging Committee acknowledged and succinctly stated the urgency of the issues elderly parents face in a 1998 forum titled, "Can We Rest in Peace? Anxiety of Elderly Parents Caring for Disabled Baby Boomers."⁷⁹ These federal initiatives underscored the need for comprehensive and multilateral support services for families with disabled relatives and cast it as a national-level policy concern.⁸⁰

72. Admin. on Aging, U.S. Dep't of Health & Human Serv., *Family Caregiving*, at <http://www.aoa.dhhs.gov/may2001/factsheets/family-caregiving.html>.

73. Older Americans Act of 1965 (as amended 2000), 42 U.S.C. §§ 3001-3058ee (2000); see also Admin. on Aging, *supra* note 72.

74. 42 U.S.C. § 3030s; see also Admin. on Aging, *supra* note 72.

75. Admin. on Aging, *supra* note 72.

76. 42 U.S.C. § 3030s-1.

77. Press Release, The White House Office of the Press Secretary, President Clinton and Vice President Gore Unveil Historic Long-Term Care Initiative to Support Family Caregivers and Help Address Growing Long-Term Care Needs (Jan. 4, 1999), available at 1999 WL 1569 [hereinafter Press Release].

78. See *id.*

79. See *supra* note 1 for citation to the witness list; substantive testimony is identified throughout this Note by particular witness and corresponding Westlaw document identification number or Internet site.

80. See Press Release, *supra* note 77.

State legislatures are also recognizing both the significance of parental care within the realm of services for the disabled and the obstacles parents face in carrying out their roles. Virginia, for example, passed the Caregivers Investment Bill, which provided a tax credit to family caregivers.⁸¹ Although not substantial enough to be considered an incentive for families to take on a caregiving duty, the bill simply acted as recognition that family caregiving is vital to the long-term care of the disabled.⁸² Other states have launched “Waiting List Initiatives” that structure social service programs to support families seeking to care for disabled children outside of an institutional setting.⁸³

These policy initiatives serve multiple functions. They acknowledge that aging parents are a significant source of support for the disabled. Furthermore, they recognize the difficulties in obtaining the necessary services and resources to continue in that role. Finally, they demonstrate that the future planning concerns confronted by both aging parents and service providers for the disabled belong within the realm of policy initiatives and directives at the state and federal levels.

III. Analysis

A. Heading Off the Crisis: Recognizing the Need to Plan and Facilitating Access to Resources

The double trauma of losing a beloved parent and then immediately relocating to an unfamiliar and perhaps unsuitable environment has become a “hidden crisis.”⁸⁴ This trauma might be avoided in many cases if the parents foresee or plan for such an eventuality,⁸⁵ but the failure to avert the crisis occurs at many levels. For various reasons, parents are unable or unwilling to accept that they may no longer be able to provide for their child one day. Because of institu-

81. Edward F. Ansello, *Legislative Advocacy: The Caregivers Investment Bill*, in *COMMUNITY SUPPORTS FOR AGING ADULTS WITH LIFELONG DISABILITIES*, *supra* note 15, at 167, 168.

82. *Id.*

83. See, e.g., *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago). These states include New Jersey, New Hampshire, Connecticut, Texas, Massachusetts, and Oregon. *Id.* These initiatives generally involve closing or consolidating institutions, diverting ICF/MR resources to HCBS resources, increasing Medicaid funding, and “expanding family support and subsidies to prevent or delay the need for placement.” *Id.*

84. See Associated Press, *supra* note 33.

85. See Stevens, *supra* note 16.

tional, budgetary, or other constraints, established service systems also fail to plan at the systemic or policy level. Addressing this dual failure is necessary in order to avoid both the emotional and economic crises.

1. A HIDDEN POPULATION WITH HIDDEN NEEDS

Lack of awareness of the issues this growing segment of the population faces both explains and describes some of the inadequacies of the current support system. The concerns of aging caregiving parents have only recently started to garner widespread concern partially because, in the past, individuals with mental retardation had a relatively short life span, most of which was spent in public institutions.⁸⁶ Moreover, these “children,” now age forty or older, were not the beneficiaries of relatively recent legislative movements providing for “improved diagnoses, mainstreaming education, and other funded interventions.”⁸⁷ As a result, when the disabled were not placed in institutions, they stayed at home, were cared for by their family,⁸⁸ and remained hidden from researchers and professionals in the aging and disability systems.⁸⁹

As of 1991, virtually no research studies regarding permanency planning for mentally retarded adults with exclusively older caregivers existed.⁹⁰ Research on caregivers of older developmentally disabled adults only began in the 1980s.⁹¹ The primary focus of studies on the disabled has not been on the families, but typically on younger individuals, institutionalized and previously institutionalized, on efforts to expand educational opportunities, or on ways to redress institutional abuses.⁹² As a result, the design of family-based programs involving both aging parents and their disabled children has been ignored by researchers,⁹³ and most families who keep their disabled

86. Matthew P. Janicki, *Symposium Overview: Aging—The New Challenge*, 26 MENTAL RETARDATION 177 (1998).

87. Edward F. Ansello & Karen A. Roberto, *Empowering Elderly Caregivers*, in THE ELDERLY CAREGIVER, *supra* note 2, at 173, 179.

88. *Id.*

89. Wood, *supra* note 2, at 95.

90. Kaufman et al., *supra* note 4, at 294.

91. LAVIN & DOKA, *supra* note 2, at 116; Roberto, *supra* note 44, at 7.

92. McCallion & Tobin, *supra* note 5, at 153.

93. Phillip G. Clark & Connie B. Susa, *Promoting Personal, Familial, and Organizational Change Through Futures Planning*, in COMMUNITY SUPPORTS FOR AGING ADULTS WITH LIFELONG DISABILITIES, *supra* note 15, at 121, 123.

children at home remain unknown to the service system.⁹⁴ Because “two-generation older families” are or will become the rule among the aging disabled population,⁹⁵ raising awareness of their issues now is essential to the task of warding off this crisis.

What little is known about the needs of aging caregiving parents is that their most pressing concerns include the availability of alternative housing, home-care assistance, financial planning for their child, and guardianship options.⁹⁶ There can be vast disparities between families in their health, financial, and overall social conditions.⁹⁷ Moreover, these conditions change over time, affecting the type of help they need.⁹⁸ Thus, comprehensive and longitudinal research is necessary to assess these needs and potential solutions more effectively.⁹⁹

2. PARENTAL FAILURE TO PLAN

“God will provide” is often a caregiving parent’s troublesome response to inquiries about his or her disabled child’s future.¹⁰⁰ Most older parents do not make definitive permanency plans that can prevent emergency arrangements and ease their family’s transition when they can no longer act as primary care providers.¹⁰¹ One of the reasons for their recalcitrance is the lack of options available to parents of disabled children fifty years ago.¹⁰² Institutions were the most prevalent solution,¹⁰³ but deplorable conditions caused them to be regarded as a “national disgrace.”¹⁰⁴ Thus, some parents chose to keep their child with them and are now in their seventies and eighties, providing direct care for a fifty-year-old disabled child.¹⁰⁵ Many provide this

94. Berkobien & Davis, *supra* note 24, at 110; Wood, *supra* note 2, at 95.

95. Berkobien & Davis, *supra* note 24, at 110.

96. See Tamar Heller & Alan Factor, *Permanency Planning for Adults with Mental Retardation Living with Family Caregivers*, 96 AM. J. ON MENTAL RETARDATION 163, 171 (1991).

97. See *id.*

98. See *id.*

99. *Id.* at 175.

100. Kaufman et al., *supra* note 4, at 297.

101. See, e.g., Christine Bigby, *Models of Parental Planning*, in COMMUNITY SUPPORTS FOR AGING ADULTS WITH LIFELONG DISABILITIES, *supra* note 15, at 81.

102. LAVIN & DOKA, *supra* note 2, at 119.

103. *Id.*

104. BRADDOCK, *supra* note 27, at 8.

105. LAVIN & DOKA, *supra* note 2, at 119.

care without ever seeking help from social service agencies for fear of having the child taken from them and placed in an institution.¹⁰⁶

In spite of the increase in services available to the disabled outside of institutional settings, only a small proportion of older caregivers use formal service systems to help with the care of their disabled family members.¹⁰⁷ Reluctance to use these services to facilitate a child's transition to the care of others is related to the "emotionally painful family separation process."¹⁰⁸ One study indicated that many parents simply do not care to think of a time in which they will need to make alternative plans for their child's care and decide instead to utilize services based only on their perception of their present ability to provide care.¹⁰⁹ Plans for future care, which generally require services that cannot be accessed on demand, are then postponed until the need for them is imminent.¹¹⁰ Avoiding this outcome requires aging parents to confront the difficult issues of their own aging and mortality, "the tension between a desire to continue caregiving and their anxiety about future care," and an acknowledgement of the interdependency between parents and their adult disabled children.¹¹¹ This anxiety and fear that no one will care for their child as they have are often enough to cause many parents to wish that they will outlive their disabled child.¹¹²

Elderly parents also tend to have a general distrust of social service agencies, which inhibits their use of available services.¹¹³ "Older parents have gone through three paradigm shifts . . . institutionalize; segregat[ion] and community programs; and community integration with supports," and over that time, "they have seen many young idealistic workers come and go . . . [making it difficult] to trust that community integration . . . will work"¹¹⁴ or that currently available

106. Associated Press, *supra* note 33.

107. Roberto, *supra* note 44, at 14.

108. Kaufman et al., *supra* note 4, at 293 (referring to a documentary that illustrated the transition of a disabled child from his residential home to a group home).

109. Jean L. Engelhardt et al., *Older Caregivers of Adults with Mental Retardation: Service Utilization*, 26 MENTAL RETARDATION 191, 194 (1988). Elderly parents also tend to want to remain primary caregivers as long as possible. Bigby, *supra* note 101, at 83.

110. See, e.g., Heller & Factor, *supra* note 96, at 163.

111. Bigby, *supra* note 101, at 84.

112. LAVIN & DOKA, *supra* note 2, at 119; Bigby, *supra* note 101, at 86.

113. McCallion & Tobin, *supra* note 5, at 159.

114. *Id.*

services will continue to exist.¹¹⁵ Such distrust deters parents from taking the initiative to seek access to services and resources that can broaden the parents' and disabled child's long-term care options within and outside of the home.¹¹⁶

Of those families that do attempt to make future plans, many go no further than placing their child's name on a waiting list for services. As discussed below, however, the system is already burdened with substantial waiting lists for residential, respite, and case management services.¹¹⁷ Thus, even for many families that claim to have plans, their plans are likely to be uncertain and subject to change.¹¹⁸

The reasons for the lack of future planning present another aspect of the problem that needs further research. There are indications that whether planning occurs, and the extent to which those plans are comprehensive and viable, correlates with socioeconomic and other demographic factors.¹¹⁹ Definitive conclusions on how such factors affect the type and extent of planning efforts, however, are speculative at best. Additional research is needed on the population, its planning habits, the outcomes of this planning, and the services needed to facilitate the planning process.¹²⁰

Raising awareness of the need to plan, and the barriers encountered in doing so, is imperative. Although much remains to be discovered about this phenomenon, there is solid evidence that services are primarily being sought only in emergency situations, which often leads to unsatisfactory remedies.¹²¹ Because crisis planning is one of the most time-consuming¹²² and expensive¹²³ responsibilities for the system's administrators, creating awareness of the need to plan and aiding in that process are important objectives for the system as well as for the families.

115. See *Supporting Families with Disabled Children: Testimony to the S. Subcomm. on Disability Pol'y of the Comm. on Labor & Human Res.*, F.D.C.H. CONG. TEST., May 10, 1994 (statement of Sue Swenson) [hereinafter *Testimony of Sue Swenson*], available at 1994 WL 232847 (indicating that being served by existing service system means "working with a stream of people who get burned out and quit").

116. McCallion & Tobin, *supra* note 5, at 159 (observing that it is difficult for older parents "to trust that sufficient support will always be available").

117. Kaufman et al., *supra* note 4, at 299.

118. Bigby, *supra* note 101, at 82-83.

119. See generally Kaufman et al., *supra* note 4, at 297.

120. *Id.* at 300.

121. Heller & Factor, *supra* note 96, at 163.

122. *Id.*

123. Hacker et al., *supra* note 15, at 440.

3. SYSTEMIC LACK OF PLANNING

The current system focuses more on individual clients with developmental disabilities than on aging families needing to make future plans.¹²⁴ Case managers, the professionals who are primarily responsible for helping these families,¹²⁵ have given little consideration to the need to assist aging parents in planning for their family's future or to developing ways to make them more willing and ready to do so.¹²⁶ The agencies' focus on "child-oriented developmental and remedial educational services and adult-oriented vocational and social developmental services"¹²⁷ has left many state agencies with a gap when it comes to preparing and aiding the elderly responsible for their care.¹²⁸ As a result, this need is "frequently unanticipated by federal, state, and local agencies, often resulting in a crisis situation" in which "many family caregivers must die before the disabled relative they care for receives appropriate services from the state system."¹²⁹

4. REMOTE SUPPORT SYSTEMS AND RESOURCES

As one parent explained to the U.S. Senate, the needed supports within the existing system are "so invisible and inaccessible at first" that they can require spending all of the family's savings before families even realize their eligibility for help.¹³⁰ Awareness of available resources is a key, but frequently missing, component in helping aging parents obtain appropriate assistance for the current and future care of their child. These aging parents, who care for their children at home for as long as they are able, have the most difficulty in accessing necessary services.¹³¹ Aging parents have unmet needs in "areas of residential program information, recreation activities, in and out-of-home respite, case management, guardianship, financial planning, and family counseling," but use few formal services to meet these needs in part because they lack information about those services.¹³²

124. McCallion & Tobin, *supra* note 5, at 153.

125. *Id.* (citing Kaufman et al., *supra* note 4).

126. *Id.*

127. Janicki, *supra* note 86, at 178.

128. *See id.*

129. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

130. Testimony of Sue Swenson, *supra* note 115.

131. LAVIN & DOKA, *supra* note 2, at 120.

132. *Id.* at 121.

Thus, they have generally little or no contact with formal systems until they are faced with a crisis.¹³³ Often no effort is made to reach out to individuals who are not already known to the system,¹³⁴ and avoiding crisis situations will require a concerted effort to reach out to older family caregivers before an emergency arises.

B. Difficulties Presented by Current Support Systems, Policies, and Resources

Upon becoming aware of their need to access available services for the immediate and long-term care of their child, aging parents encounter the ensuing hurdle: the shortcomings of a system that is meant to support them and their disabled child as they age. They face service “packages” that provide more or less than what they seek,¹³⁵ daunting waiting lists for urgently needed services, and policies that impede their efforts to arrange for adequate care of their disabled child. These factors make the system seem hostile to the increasing numbers of older parents who need to access services or benefits on behalf of their disabled children.

1. THE “SYSTEM KNOWS BEST” APPROACH TO SERVICE PROVISION

The current service system is unresponsive to varying family situations, their corresponding differences in needs, and changes in these needs over time.¹³⁶ The system’s offerings often lack the adaptability needed to adequately meet the concerns of elderly caregivers.¹³⁷ For example, one family might find it difficult to get an elevator lift installed in their home so that the family can move a wheelchair-bound individual with greater ease and safety.¹³⁸ This same request, however, could be met with less resistance if there was a personal care assistant for whom the elevator lift would be required in order to comply with the lifting regulations of the Occupational Safety and Health Administration.¹³⁹

133. Kaufman et al., *supra* note 4, at 293.

134. See, e.g., Testimony of Sue Swenson, *supra* note 115.

135. *Id.*

136. See, e.g., Heller & Factor, *supra* note 96, at 175 (suggesting the need for more studies that consider changes in a family’s needs and support resources that occur as they age).

137. See Kaufman et al., *supra* note 4, at 293 (stating that services should allow for changes in needs and circumstances).

138. Testimony of Sue Swenson, *supra* note 115.

139. *Id.*

Part of the reason why aging parents have difficulty navigating the system is that their election to care for their disabled child at home is often met with resistance by their supposed allies in the system, the case workers.¹⁴⁰ Research indicates that as a group, these professionals “deplor[e] the infantilization of adult sons and daughters” and the aging parent’s “resistance to making permanency plans.”¹⁴¹ This viewpoint could explain the lack of regard given to the choices and concerns of parents.¹⁴² Moreover, the reproachful stance of those workers also explains the parents’ reluctance to turn to them for assistance.¹⁴³

This system and service provider-centered approach negates the role of the family when determining the type and amount of public resources they will receive.¹⁴⁴ The implications of such inflexibility leave families with the option of taking more or less help than they want or need, or not taking any assistance at all.¹⁴⁵ Older caregivers, case workers, and those who finance the system should be concerned when the provision of services is unnecessarily conditioned upon the imposition of other nonessential, resource-consuming mechanisms.¹⁴⁶

2. LONG WAITING LISTS FOR LIMITED RESOURCES

Once aging parents request the support they need from state agencies,¹⁴⁷ they are informed of the waiting lists for those services and supports.¹⁴⁸ These waiting lists are a function of shortages in funding and service providers,¹⁴⁹ as well as the low legislative priority

140. See McCallion & Tobin, *supra* note 5.

141. *Id.* at 154. Case managers “are the primary professionals who have the responsibility of assisting families in making such plans.” *Id.* (citing Kaufman et al., *supra* note 4).

142. *Id.* at 153.

143. See *id.* at 161; see also Testimony of Sue Swenson, *supra* note 115. “We often have been advised to institutionalize [our son] . . . the system even seems to be waiting patiently to watch us fail so that it can swoop in and say ‘I told you so.’” *Id.*

144. See generally Testimony of Sue Swenson, *supra* note 115 (“The system controls the money, it controls the options and the choices, it makes the decisions.”).

145. *Id.*

146. *Id.* More resources are allocated for the compliance with regulations that control the provision of services than for the provision of services themselves. See Berkobien & Davis, *supra* note 24, at 111. Agencies often have to develop services that prioritize regulation compliance over meeting individual consumer needs. *Id.*

147. *Can We Rest in Peace?*, *supra* note 1, at <http://www.senate.gov/~aging/f8jg.htm> (testimony of Jackie Golden, parent of a disabled child).

148. *Id.*

149. Symposium, *supra* note 46, at 126.

given to programs for the developmentally disabled.¹⁵⁰ The problems posed by these waiting lists are even more urgent for aging parents given that they tend to seek these services when they are close to or at the point at which they can no longer provide for their child's care.

Among the longest waiting lists are those for supplies not covered under private insurance: respite services, day programs, or residential services that could provide the disabled child and his or her family with greater independence.¹⁵¹ These waiting lists indicate that families often have to do without these resources for extended periods of time.¹⁵² For example, families seeking or requiring placement outside of the family home face "long waiting lists and few acceptable options," given the "large gaps in the residential service system."¹⁵³ In 1996, there were 83,101 people with developmental disabilities on waiting lists for residential services alone.¹⁵⁴

One Maryland study showed that half of the individuals on the waiting lists for state residential services lived at home with parents over the age of sixty.¹⁵⁵ Given Maryland's large population, this "percentage of aging caregivers . . . may well closely approximate the national pattern."¹⁵⁶ A 1997 survey indicated that 218,186 service requests for the mentally retarded were placed on waiting lists.¹⁵⁷ This data, however, did not include those individuals waiting to move

150. *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1350 (S.D. Fla. 1999).

151. *See id.*

152. *Id.*

153. Tamar Heller, *Aging Caregivers of Persons with Developmental Disabilities: Changes in Burden and Placement Desire*, in *THE ELDERLY CAREGIVER*, *supra* note 2, at 21, 38.

154. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago). Some states do not keep official lists and some might provide inaccurate data, indicating that this number could be higher. *See id.* (noting that Illinois indicated zero persons, yet the state lags behind others in developing family-scale residential alternatives).

155. *Homeless Housing Programs: Testimony Regarding Housing and Development Reauthorization Legislation Submitted by the Consortium for Citizens with Disabilities Housing Task Force Before the H.R., F.D.C.H. CONG. TEST.*, Apr. 26, 1994, (testimony of Kate Rollason, Executive Director, The Arc of Southern Maryland) [hereinafter *Kate Rollason Testimony*], available at 1994 WL 230501.

156. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago). One report cited 4,682 persons waiting for services, thirty-nine percent of whom lived with caregivers over age sixty, twenty-four percent with caregivers over age seventy, and fourteen percent with caregivers over age eighty. *Id.*

157. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago) (citing survey by The Arc).

from institutions into the community and, therefore, it is considered an understated number given the difficulty in collecting accurate information from varying state systems.¹⁵⁸ Trends show that lists will continue to grow absent a concerted effort to redress the shortage.¹⁵⁹

States “have faced lawsuits challenging the fairness of their waiting lists for the developmentally disabled.”¹⁶⁰ Citing a provision in the Medicaid Act that requires eligible beneficiaries to receive assistance under the Medicaid plan with “reasonable promptness,” various courts have created a right of action against states when such delays are found unreasonable.¹⁶¹ Notably, when the claimants are families caring for older adult disabled children, their children’s age appears to bear on the question of what is considered reasonable.¹⁶² Challenging the waiting lists in court has been one approach used to bring the problem to the forefront of state policy agendas.¹⁶³

3. MINIMAL FOCUS ON HOME-BASED LONG-TERM CARE

A vital component of the waiting list problem is the current focus of the Medicaid program. The Medicaid program, which funds

158. See *supra* note 155 and accompanying text; see also *Boudreau v. Ryan*, No. 00 C 5392, 2001 WL 840583, at *2 (N.D. Ill. May 2, 2001) (“The State of Illinois does not have a waiting list for granting eligible individuals residential Medicaid Services.”).

159. Kate Rollason Testimony, *supra* note 155.

160. Associated Press, *supra* note 33 (citing Tamar Heller, a researcher at the University of Illinois-Chicago’s Institute on Disability and Human Development).

161. *Boudreau*, 2001 WL 840583, at *8–9 (finding that plaintiffs, as developmentally disabled or mentally retarded adults, some living with elderly parents, have an enforceable federal right under the Medicaid Act); *Lewis v. N.M. Dep’t of Pub. Health*, 94 F. Supp. 2d 1217, 1236 (D.N.M. 2000) (finding that remaining on a waiting list for two to seven years violated reasonableness requirement); *Boulet v. Cellucci*, 107 F. Supp. 2d 61, 63–64, 79 (D. Mass. 2000) (holding that the reasonable promptness obligation was violated in a case involving plaintiffs ranging in age from twenty-five to forty-five, all of whom lived with their parents and had been on a waiting list from three to more than ten years, plaintiffs asserted that represented class included at least 3,000 people). Plaintiffs have been held to have an enforceable right of action against the state based on the federal Medicaid Act’s reasonable promptness provision even when they seek Medicaid waiver services associated with the Home and Community Based Care program, which is an optional service. *E.g.*, *Bryson v. Shumway*, 177 F. Supp. 2d 78, 94 (D.N.H. 2001) (“When a state elects to provide an optional service, that service becomes part of the state Medicaid plan and is subject to the requirements of federal law.” (internal quotes and citations omitted)).

162. See *Boulet*, 107 F. Supp. 2d at 63–64.

163. See Associated Press, *supra* note 33 (stating that “lawsuits are aimed at getting the attention of each states’ policy makers,” citing Tamar Heller, a researcher at the University of Illinois-Chicago’s Institute on Disability and Human Development).

much of the disability system, fails to reflect the shift away from institutionalization towards family and community-based care; instead, it retains its “bias in favor of institutionalized long-term care.”¹⁶⁴ The majority of Medicaid funds continue to be deployed to institutions.¹⁶⁵ Of the sixty-eight billion dollars in Medicaid funds spent on long-term care in fiscal year 2000, only eighteen billion dollars, or twenty-seven percent, was spent on home and community-based services.¹⁶⁶ The ICF/MR program, which states use to fund their institutions, remains the largest federal mental retardation and developmental disability services program.¹⁶⁷ The funding it receives more than doubles the funding of the HCBS waiver program, which promotes home and community-based services and represents the second largest recipient of Medicaid funding.¹⁶⁸

Some states have started the shift towards pursuing HCBS Medicaid waiver funds, a trend that has followed the closing of public residential institutions and the expansion of community residential living services.¹⁶⁹ The Medicaid system, however, is not structured to facilitate this transition and, as a result, few states have been able to meet their institutional needs while still furthering their home and community-based service objectives.¹⁷⁰ Due to the high costs of both systems, states cannot usually pursue both simultaneously.¹⁷¹ The implication is that because of limited funds, a state cannot shift its focus from the institutional system to the home and community-based support system because it would need to maintain the institutional system while expending significant resources to create the alternative.¹⁷² Thus, while there is a popular preference towards home and community-based care, the institutional model still prevails.

The Medicaid HCBS waiver program’s “cap” system also limits an aging parent’s access to support services for his or her disabled child’s long-term care. States and Medicaid-centered agencies gener-

164. Batavia, *supra* note 60, at 23.

165. BRADDOCK, *supra* note 27, at 25.

166. *Long Term Health Care, U.S. Gen. Accounting Office Testimony Before the Special Comm. on Aging, U.S. S. (2001)* (statement of Kathryn G. Allen, Director, Health Care-Medicaid and Private Health Ins. Issues), at 2001 WL 26186491.

167. BRADDOCK, *supra* note 27, at 25.

168. *Id.*

169. *Id.* at 16.

170. *Id.*

171. *Id.*

172. Kane et al., *supra* note 61, at 371.

ally apply for and receive a limited number of waiver slots in effort to control costs and out of fear that individuals and their family caregivers will “come out of the woodwork” to burden the system.¹⁷³ The acknowledged cost of these limits, however, is having waiting lists for services¹⁷⁴ including personal care, case management, home health, and respite,¹⁷⁵ all of which parents of disabled children require with increased urgency as they age.

Thus, Medicaid, a primary source of funding for the disabled, remains “very biased towards institutions,”¹⁷⁶ even though the use of institutional long-term care has drastically diminished¹⁷⁷ and families have played a dominant role in assuming the responsibility for such care.¹⁷⁸ This “institutional bias” is partly due to strong political pressure from existing service providers to maintain and expand their share of Medicaid funds.¹⁷⁹ With Medicaid comprising a significant source of funding for long-term care institutions, they have a strong incentive to lobby for the protection of their interests.¹⁸⁰ In sum, the assistance given to institutions, though still necessary, is disproportionate in light of the shift towards families as a primary source of caregiving.¹⁸¹

4. PUBLIC FUNDING PROGRAMS PENALIZE PRIVATE PLANNING

Another problem with the current system of public assistance is that it penalizes parents even when they do plan for their children’s

173. Symposium, *supra* note 46, at 120.

174. Kane et al., *supra* note 61, at 371 (citing U.S. GAO 1994).

175. See *supra* notes 59–71 and accompanying text regarding Medicaid and the services for which it provides.

176. See *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 664474 (statement of Lorraine Sheehan).

177. “The census [of individuals residing in state-operated institutions] will continue to decline in future years as it has for every one of the past 30 years.” BRADDOCK, *supra* note 27, at 16.

178. *Can We Rest In Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

179. Kane et al., *supra* note 61, at 371.

180. Cf. Karl Kronebusch, *Medicaid and the Politics of Groups: Recipients, Providers, and Policy Making*, 22 J. HEALTH POL. POL’Y & L. 839, 860–61 (identifying medical service-providing entities, like nursing homes, as lobbyists and active participants in Medicaid policymaking in light of their high stakes in Medicaid spending). These entities derive their “structural power” from being well organized and providing vital medical services to the public. *Id.* at 861.

181. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago).

future.¹⁸² Under the primarily need-based system, assets left to a disabled child can lessen or eliminate benefits, resulting in a private expense for otherwise public benefits, even for such expenses as institutionalization in state hospitals.¹⁸³ Thus, parents of “moderate resources” find their attempts to leave some sort of financial support for their adult disabled child rendered “unwise” by the system, and they must resort to complex estate planning to avoid jeopardizing the public benefits that their child might need even after taking the family’s private funds into account.¹⁸⁴

As adults, the disabled could become eligible for assistance under the Social Security Act’s Supplemental Security Income (SSI)/Medicare program.¹⁸⁵ Recipients, however, cannot exceed the level of income and assets Congress sets each year.¹⁸⁶ The set income level generally also determines eligibility for Medicaid.¹⁸⁷ Under this need-based system, families who engage in financial planning by making their disabled children beneficiaries of any assets might find that Medicaid and SSI penalize the beneficiaries if the inheritance ruins their eligibility.¹⁸⁸ This outcome is especially tragic when the private assets are insufficient to cover all of the disabled child’s needs, yet the amount results in the loss of substantial public benefits.¹⁸⁹ “For example, leaving assets of more than \$2000 to an individual with disabilities might result in the loss of Medicaid benefits and health care.”¹⁹⁰

The system is therefore as fraught with peril for those aging parents who try to plan as well as for those who do not. A family with

182. FROLIK & BROWN, *supra* note 59, ¶ 12.5[2], at 12-30.

183. *Id.*

184. *Id.* ¶ 12.5[1], [2], [2][a], at 12-30 to 12-31; *see also* Jan L. Warner & Jan Collins, *Planning for Disabled Child Essential at Divorce*, NEXT STEPS (Apr. 10, 2000), at <http://www.nextsteps.net/articles/105.asp> (last visited Feb. 22, 2002).

185. LAVIN & DOKA, *supra* note 2, at 113.

186. FROLIK & BROWN, *supra* note 59, ¶ 12.2[4], at 12-11, 5.1[1], at 5-3.

187. LAVIN & DOKA, *supra* note 2, at 113.

188. *Id.* at 125 (“[A] forty-five-year-old woman with mental retardation . . . inherited \$100,000 upon the death of [her] mother . . . she lived in a state-funded residential facility, [and] Medicaid authorities accessed the funds as payment for her care, leaving her with nothing.”); *see also Supplemental Security Income: Oversight Hearing Before the Subcomm. On Human Res., Comm. on Ways & Means, F.D.C.H. CONG. TEST.*, Oct. 14, 1993 (Testimony of Julie Renda, representative for Alliance For the Mentally Ill) [hereinafter Julie Renda Testimony], available at 1993 WL 748170 (asset level limit of SSI recipients does not allow parents to provide for their children’s future needs).

189. *See* FROLIK & BROWN, *supra* note 59, ¶ 12.5[2], at 12-30.

190. LAVIN & DOKA, *supra* note 2, at 125.

just enough resources to provide their son or daughter with a home or assets to put them just above the SSI cap will be penalized and forced to “spend down” to the near-subsistence level required for SSI eligibility.¹⁹¹ For example, if a child inherited a home, it is likely that his or her SSI income alone will be insufficient to pay taxes and maintenance. The home would therefore have to be sold with the conversion of assets then bringing the child above the allowed asset level until the amount was spent down to the necessary level.¹⁹² Thus, the current eligibility requirements thwart one of the primary means of support for disabled and older individuals. Aging parents seeking some degree of assurance that they will be able to provide for their children may wish to lessen the burden on taxpayers but find that they cannot without jeopardizing their children’s eligibility for public support.¹⁹³

C. Divergent Aging and Disability Networks

As parents are less able to provide care, they require more services.¹⁹⁴ Theoretically, they have two vast service systems from which they could derive such support—the aging and disability systems. Medicare and the Older Americans Act make federal funding available to those two systems,¹⁹⁵ although both have traditionally kept themselves separate from one another.¹⁹⁶ Moreover, neither “the aging nor the disabilities services system is prepared for the rapid growth” in the population of older disabled individuals.¹⁹⁷ Often, service providers within the aging or developmental disabilities systems focus specifically on “the population understood and not the family unit.”¹⁹⁸ Thus, instead of acting as tandem support systems for aging parents and their disabled children, parents find themselves in a situation where someone otherwise well versed in advising an elderly individual in terms of future long-term care and financial planning would not know how to include a disabled adult child in those plans. Conversely, a case worker familiar with meeting the needs of younger

191. See Julie Renda Testimony, *supra* note 188.

192. *Id.*

193. See *id.*

194. See Roberto, *supra* note 44, at 15.

195. LAVIN & DOKA, *supra* note 2, at 116.

196. *Id.* at 91.

197. Constance L. Coogle et al., Partners II, *Serving Older Persons with Developmental Disabilities: Obstacles and Inducements to Collaboration Among Agencies*, 14 J. APPLIED GERONTOLOGY 275, 275 (1995).

198. McCallion & Tobin, *supra* note 5, at 159.

disabled clients might not be aware of the specific needs of an older family in areas such as estate, recreational, or alternative residential planning.

There are many barriers keeping disabled individuals from inclusion in regular aging services, ranging from “attitudes of . . . providers . . . to issues of information, communication, financial, programmatic, and . . . other obstacles.”¹⁹⁹ Moreover, the lack of cooperation between the two systems arises naturally “[g]iven [their] disparate origins, mandates, delivery mechanisms, orientations, and clientele.”²⁰⁰ The Medicaid program, for example, serves very diverse groups including the elderly, the disabled, “children in low-income families, and adults receiving Aid to Families with Dependent Children,” all of whom are competing beneficiaries of the program’s resources.²⁰¹ Thus, instead of being able to obtain the services they need by virtue of being eligible for services from two large support systems, families with aging and disabled individuals find themselves falling between the gaps of both.²⁰²

The practical effect of this exclusion on aging parents is that there is no one agency that can help coordinate the services to meet their current needs and simultaneously help them to prepare and execute a plan to meet their children’s future needs.²⁰³ One temporary federally funded project was established to explore the ways in which disability and aging services coalitions for “two-generation older families” could come together to provide support for them.²⁰⁴ Some problems, aside from the project’s short duration, were rooted in the “isolated place that developmental disabilities services have created for themselves,”²⁰⁵ the residual history of providing services in segregated environments, and the lack of prior collaboration between the aging and developmental disabilities systems.²⁰⁶ What the study did

199. Berkobien & Davis, *supra* note 24, at 110 (citing a 1993 Janicki study).

200. LAVIN & DOKA, *supra* note 2, at 91.

201. Kronebusch, *supra* note 180, at 840.

202. LAVIN & DOKA, *supra* note 2; Berkobien & Davis, *supra* note 24, at 111. Providers have kept services for individuals who are aging separate from services for individuals with developmental disabilities. *Id.*

203. See Berkobien & Davis, *supra* note 24, at 110 (citing an example of an eighty-year-old father caring for his fifty-five-year-old son by himself after his wife’s death and their need for an agency that could coordinate services to address his deteriorating health and assist with planning for his son’s future).

204. *Id.* at 113.

205. *Id.* at 115.

206. *Id.* at 114.

produce was a greater realization of the need to form these coalitions, focusing on optimizing the “services and supports for aging people with developmental disabilities . . . [and] for a significant investment in training to assist aging parents in planning for the future of their adult children.”²⁰⁷ Also apparent was the need for interagency statements of collaboration “to support coalition building at the community level.”²⁰⁸ These coalitions, while striving to coordinate services to meet the needs of both aging parents and children,²⁰⁹ may gain the advantage of being more effective and efficient by avoiding duplication and overlap of services.²¹⁰

IV. Recommendations

A. Mandate Further Research

The lack of research on issues confronting elderly parents of disabled individuals is an obstacle to policy development.²¹¹ Therefore, one of the first policy initiatives should be to explore the specific issues faced by aging parents of dependent adults.²¹² When it comes to this population, existing knowledge is hardly enough to alert the current system to their pressing needs, and even less is known about what may be required to formulate viable and comprehensive plans to address these needs.²¹³ Various factors, such as culture and race, may affect long-term care decisions.²¹⁴ Presumably, no single approach or “service package” will satisfy every family’s needs. More research identifying the needs of aging caregivers also helps policy makers²¹⁵ and service providers identify what services families need.²¹⁶ Thus,

207. *Id.* at 115.

208. *Id.* at 114.

209. *Id.* at 110.

210. *Id.* at 123.

211. LAVIN & DOKA, *supra* note 2, at 117; Bigby, *supra* note 101, at 55.

212. See Louis Rowitz, *Caregiving—A Lifetime Concern*, 26 MENTAL RETARDATION iii, iv (1988) (indicating that the idea of parents providing lifetime care to handicapped individuals is a fairly recent “crossover concept” that needs to be “addressed and explored in great detail . . . [to] provide services that are appropriate to the needs of a given family.”).

213. McCallion & Tobin, *supra* note 5, at 161.

214. Janicki, *supra* note 86.

215. See Wood, *supra* note 2, at 106.

216. Ellie Brubaker & Timothy H. Brubaker, *Caring for Adult Children with Mental Retardation, Concerns of Elderly Parents*, in THE ELDERLY CAREGIVER, *supra* note 2, at 51, 60.

systematic analysis of the varied issues facing older caregivers in order to fashion innovative programs for these families is needed.²¹⁷

B. Making Existing Support Services More Accessible

Current service providers should be trained to be more proactive in reaching out to these families and be more responsive to their needs.²¹⁸ Understandably, where resources are limited, “systematic outreach may not be a priority.”²¹⁹ Thus, service providers must have solid policy guidance focusing upon raising awareness about available resources and the needs of aging caregivers.²²⁰ Governmental and service agencies must encourage outreach to parents who become the long-term care providers for their child.²²¹ Such efforts should strive to overcome the parents’ resistance to planning by putting them in contact with service providers who can help them.²²² Moreover, early contact is a necessary element in a care system that has saved a significant amount of money due to the efforts of those parents who choose to provide for their child’s care.²²³

One way to raise awareness of government initiatives and resources is to inform parents when the child is born or diagnosed with a disability that assistance is available *but not to be imposed*.²²⁴ At that point, the government can provide counseling to explore caregiving alternatives, assess the family’s available resources, and work on identifying the type and extent of future assistance needed.²²⁵ Given that family caregivers are often concerned about incessant interference by the government or other service providers, this approach could be useful because it would focus on disseminating information about

217. See Clark & Susa, *supra* note 93 at 123.

218. Karen A. Roberto, *Older Caregivers of Family Members with Developmental Disabilities, Changes in Roles and Perceptions*, in *THE ELDERLY CAREGIVER*, *supra* note 2, at 39, 49.

219. Coogle et al., *supra* note 197, at 283.

220. See *id.*

221. See *supra* notes 90–94 and accompanying text (indicating that older family caregivers tend to be “invisible” to the current service-providing system).

222. See McCallion & Tobin, *supra* note 5, at 161 (indicating that more research is needed to establish the most effective ways to accomplish this goal).

223. See Family Caregiver Alliance, *Fact Sheet: Selected Long-Term Care Statistics* (Sept. 2001), at http://www.caregiver.org/factsheets/long_term_statsC.html (last visited Aug. 20, 2002) (estimating that informal caregiving has a value of \$196 billion, more than the value of nursing home care (\$83 billion) and paid home care (\$32 billion) combined).

224. See Testimony of Sue Swenson, *supra* note 115.

225. Kaufman et al., *supra* note 4, at 299.

available services. Thus, it would let families keep track of “the system” and what it has to offer, instead of having the system keep track of them, at least until they can select those services that best fit their needs.

C. Working with Existing Resources

Deinstitutionalization has not translated into a comprehensive system of community services to help parents of the disabled.²²⁶ Unfortunately, the resources saved from closing institutions have not always been redirected to alternative models of long-term care, such as the home and community-based systems.²²⁷ Fears that potential beneficiaries will exceed the capacity of any home or community-based program are unfounded given the higher per capita cost of providing institutional care. Transferring the prior resources expended on that care to home and community-based services would help more beneficiaries but use the same amount of funding. Moreover, the increased demand for home and community-based support services is grounded in a real demand for these services. Rarely does such a pressing need disappear simply by ignoring it. Even if funding such a system of support exceeds current means, the effort to assist elderly parents in providing for their handicapped children is still necessary, both for economic and moral reasons. Emergency cases in which a child is suddenly thrust into the formal service system are the most expensive and time consuming to handle.²²⁸ Keeping in mind the population growth and trends indicating that such situations are likely to increase, the ensuing burden on the system could lead to neglect of other cases and functions, creating a bottleneck in service provision which, in turn, would increase the number of individuals in danger of experiencing the crisis.

The little research that exists suggests that changing the system to make it more responsive to the needs of aging parents does not

226. Rowitz, *supra* note 212, at iv.

227. See, e.g., *Lewis v. N.M. Dep't of Pub. Health*, 94 F. Supp. 2d 1217 (D.N.M. 2000) (finding in a more egregious example that plaintiffs had a claim against the governor for failing to provide waiver services when the savings obtained by moving developmentally disabled persons from receiving needed services to waiver programs were used for the general fund and caused delays in providing the waiver services).

228. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 667681 (statement of Dr. David L. Braddock, Professor, University of Illinois at Chicago) (testifying about most expensive level of care).

necessarily require more funding, but a more efficient allocation of existing resources.²²⁹ Private and public service providers can modify their approaches to provide services to family caregivers as they age. For example, Rhode Island reported having no waiting lists because it has used savings from the institutions they closed to fund community services.²³⁰ As of 1998, three states developed five-year plans to eliminate their waiting lists through funding shifts.²³¹

The federal government could aid in this transition by helping those states that are attempting to phase out institutions but find the costs of simultaneously developing family and community-based supports prohibitive.²³² Under the “old system” of institutionalization, the cost of providing full care significantly outweighed the cost of providing supports to have the individual accommodated in the home or other community settings.²³³ In New Hampshire, for example, the expenditure under the traditional system doubled what was spent under a plan in which disabled individuals and their families determined their own needs and how to efficiently allocate the resources available to them through the state.²³⁴ During the transition period, the federal government should continue to provide the states with funding to sustain institutions even as they close and the number of people served declines. States could then allocate the difference between the resources required to sustain the former system toward the new home and community-based system.

Policies should also seek to curtail the extent to which Medicaid disproportionately funds institutional systems as a result of political pressure rather than actual consumer demand. Moreover, policies should enable families of the disabled to bequest support for basic necessities, such as homes, to facilitate the option of remaining with the

229. See Julie Renda Testimony, *supra* note 188.

230. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 664474 (statement of Lorraine Sheehan, chairperson of The Arc’s Governmental Affairs Committee).

231. *Id.* The states are New Jersey, Maryland, and New York. *Id.*

232. See *supra* notes 69–71 and accompanying text.

233. See, e.g., *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 664471 (Testimony of Thomas Nerney and Donald Shumway, directors, New Hampshire Institute on Disability). But see Kronebusch, *supra* note 180, at 859 (indicating that some evidence suggests that many home- and community-based services are “unlikely to be cost saving”). One reason for this discrepancy is political and can be attributed to the ability of nursing homes to “resist cutbacks in funding their services, even when community based services are being expanded.” *Id.* at 873.

234. *Can We Rest in Peace?*, *supra* note 1, at 1998 WL 665571 (testimony of Thomas Nerney and Donald Shumway, directors, New Hampshire Institute on Disability).

family without jeopardizing Medicaid eligibility. In short, the government's allocation of funds should more closely reflect the types of support that are currently in demand,²³⁵ meaning that greater consideration should be granted to home and community-based long-term care programs as opposed to the formal institutional care system. States have observed a marked increase in such demand, thus making them fear that accommodating it will be very burdensome.²³⁶ Moreover, more people might be eligible for such services than the traditional institutional-based support. Nevertheless, the state's fears are ill placed. While such a system might serve more people, the per capita cost will be significantly lower than institutional care. Effective case management can also be used to "stem the tide" of potential system abuse.²³⁷ States must devise flexible and innovative approaches to meeting a demand for family support services using those resources that support its existing service framework.

D. Encourage Intersystem Collaboration

As these parents age, their needs extend beyond their own long-term care to include a need to plan for their disabled child's long-term care as well. General welfare resources and services for the aging and the disabled are limited.²³⁸ Research indicates that "code, law, or statutory mission is most often used to determine the clientele that an agency serves . . . [and that] these legal bases also operate as barriers."²³⁹ Thus, service professionals must focus on identifying and providing access to services from the broader and cumulative array of those benefits offered to the disabled, the aged, and general public services.²⁴⁰

These efforts, however, must be prompted and unified under a national policy directive.²⁴¹ The National Family Caregiver Support Program, by mandating that family caregivers receive information

235. See generally *supra* note 1.

236. See Kane et al., *supra* note 61, at 371. Providing community-based long-term care will induce demand by virtue of offering a better product. *Id.*

237. See *id.* (indicating that this contention has been advanced, although met with skepticism).

238. Jean P. Lehman & Karen A. Roberto, *Current and Future Service Needs of Aging Individuals with Developmental Disabilities Living with Relatives*, in THE ELDERLY CAREGIVER, *supra* note 2, at 121.

239. Coogle et al., *supra* note 197, at 282.

240. Lehman & Roberto, *supra* note 238, at 121.

241. See *id.*

about available support services and assistance,²⁴² is a step in the right direction. Unfortunately for the aging parents of the disabled, the existing regulations only help family caregivers who care for older individuals or older caregivers caring for a child no more than eighteen years of age.²⁴³ Parents of disabled children should be remembered in national policy efforts to provide multilateral comprehensive guidance and options. A unifying national directive can make the provision and dissemination of these services more efficient. This is presumably the purpose behind having the Caregiver Support Program include an assistant secretary to evaluate and promote the initiative among the states so as to enable them to incorporate effective approaches into their own programs.²⁴⁴

V. Conclusion

The formal support systems that exist for the elderly and disabled are unprepared for the increasing number of elderly caregivers who do not seek help from the system until they face a crisis. A multilateral, flexible effort on a broad policy level is needed to accomplish several goals. First, a “continuous interactive loop (research to policy to practice to research)” must be established to empower elderly caregivers²⁴⁵ and to raise awareness of their needs. Second, existing programs must recognize the need to relieve elderly parents’ anxiety over planning for their child’s long-term care and to overcome the barriers they face when they do try to plan for it. Finally, public resources must be kept from being inefficiently spent on massive state institutions, inflexible service “packages,” and handling “crisis” cases. This approach begins with the realization that aging parents are a significant source of support for disabled individuals but that they are in need of support themselves. Helping them to help themselves will require significant changes in the way that the aging and disability systems operate.

242. 42 U.S.C. § 3030s-1 (West 2000).

243. *Id.* § 3030s.

244. *Id.* § 3030s-11.

245. Ansello & Roberto, *supra* note 87, at 173.