

**THE COSTS OF TRIPLE JEOPARDY:  
AGING, DEVELOPMENTAL DISABILITIES,  
AND OHIO'S IMPENDING CARE SHIFT**

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### **A note about language.....**

Recent developments in the use of the term *mental retardation* have forced a difficult choice in the writing of this report. In 2001, the Board of the American Association on Mental Retardation unanimously proposed a name change, to the American Association on Intellectual Disabilities. (For pros and cons related to the decision, see

[http://www.aamr.org/pro\\_memo.shtml](http://www.aamr.org/pro_memo.shtml) and [http://www.aamr.org/con\\_memo.shtml](http://www.aamr.org/con_memo.shtml).

For a comprehensive debate on the issue, see *Mental Retardation* (2002) Vol. 30, No 1., 51-83)

Because Ohio continues to use mental retardation in most of its bureaucratic, legal, and programmatic language, we have kept the term in most of the text of our report. Where appropriate, we have used the term *intellectual disability*, in deference to the growing use of this language.

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## **THE COSTS OF TRIPLE JEOPARDY: AGING, DEVELOPMENTAL DISABILITIES, AND OHIO'S IMPENDING CARE SHIFT**

Today, all across the State of Ohio, families unimaginable fifty years ago go about living a way of life they have created out of their own well of devotion, energy, and resourcefulness. These are Ohio's "Double Jeopardy"<sup>1</sup> families, dealing with the dual, co-residing challenges of aging *and* developmental disability. Double Jeopardy families represent a combination of both anticipated and unanticipated challenges related to aging. While we have anticipated the aging of baby boomers, born between 1946 and 1964, we did not anticipate the level of survival of baby boomers *with developmental disabilities* into the 21<sup>st</sup> Century. For example, the average life expectancy of individuals born with Down Syndrome in the 1930s was 9; by 1983, it was 25; life expectancy then doubled in just fifteen years, to age 49, where it now stands.<sup>2</sup> And, while the general population has enjoyed incremental increases in life expectancy over the last half-century, we did not anticipate that most of the recent increase would be attributable to the survival of the "oldest old."

Most of Ohio's Double Jeopardy families are composed of baby boomers with developmental disabilities and their aging parents, in their 70s and 80s. For the most part, these parents have not expected their children to outlive them, and they find themselves in the once unforeseeable circumstances of *lifelong* "perpetual parenthood"<sup>3</sup>. They bore children in a time when institutionalization was a common recommendation of professionals, friends and family. They bore children into communities with little else in the way of services. Ultimately, they were the pioneers who forged their way through a wilderness of ignorance, stigma, and indifference to claim attention for their children and instigate the development of a system of services. Through it all, these parents kept their children at home and made families of themselves. Today, they represent that network of care known as informal caregivers, providing uncompensated, in-home care and support; some are assisted by the formal system of care provided mostly through county boards, and some are not.

These families are called Double Jeopardy families because they are "at risk" in two ways: 1) the individual with a developmental disability requires care and support, while 2) the older family member(s) may require care and support. Complicating the state of jeopardy are two critical issues: 1) the individual with a developmental disability is also experiencing the effects of his or her own aging (often accelerated), and 2) the aging caregivers may die or otherwise lose capacity to sustain care.

If these are Double Jeopardy families, Ohio is a Triple Jeopardy state. Ohio has: 1) aging individuals with developmental disability who are about to lose their primary system of support; 2) aging caregivers who may need care themselves and who are likely to lose capacity to provide care; and 3) a long-term care system, in both the aging network and MR/DD, already unable to meet *existing* need and facing an imminent and significant increase. Ohio's Legislative Budget Office estimates that there are currently 6,500 individuals on waiting lists for residential

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<sup>1</sup> Ohio Department of Aging, 2001. *Final Report to Administration on Developmental Disabilities*, Grant # 90DF0011.

<sup>2</sup> Yang Q, *et al.* (2002) *Lancet* 359:1019-1025.

<sup>3</sup> Attributed to Sheldon Tobin.

services.<sup>4</sup> The number of very old Double Jeopardy families is expected to double by 2030<sup>5</sup>; the impact of Triple Jeopardy will only intensify with time.

## Chapter 2 Care Shift – Cost Shift

Reliance on family care has long been part of our culture, our politics, and our policy. Nationally, over 80% of long-term care is provided in-home, by uncompensated family members<sup>6</sup>. Arno *et al*<sup>7</sup> estimate that the economic or market value of that care is \$196 billion annually. With a significant portion of its budget expended on formal long-term care services<sup>8</sup>, Ohio has benefited from the willingness of its families to provide housing, care, and support for members with chronic illness or disability. Approximately 60% of individuals with a developmental disability live with family, and another 15% live with a spouse.<sup>9</sup> This arrangement declines with age, however. As aging caregivers of individuals with developmental disability die or become disabled themselves, new sources of care and support must be found, within the extended family, in the formal service system, or in some combination of the two. This presents a *care shift*; it is inevitable, imminent, and loaded with costs. This shift is made particularly dramatic by two factors affecting the same age group: it is the largest age group and it is also the first age group to have such long life expectancy. The care shift will not happen all at once, and it will go on indefinitely. It will not disappear with the passing of the Baby Boom; as long as we continue to rely heavily on family support, particularly the support of parents, we will need to have a system in place to care for this kind of shift, family after family.

While we have always relied on family care as the base of support for individuals with developmental disabilities, in the formal care system we moved from institution-based, facility-centered care, to home-and-community-based, person-centered care. The impending care shift actually follows a series of shifts that have taken place in the formal care networks of both aging and MR/DD. First, both fields experienced shifts from institutional to home and community based care, albeit at different times. The 1970s was a time of rapid expansion of nursing home construction and placement, fueled largely by Medicaid dollars. At the same time, deinstitutionalization of people with developmental disabilities from state facilities resulted for a time in the transinstitutionalization of residents into nursing homes and ICF-MRs. Group homes were developed to provide care and support in the community for the MR/DD population. For both aging and MR/DD, the late 1980s and 1990s were characterized by a transition in emphasis from nursing home and other institutional care to home and community based care. An important shift occurring in the last decade has been in the move to what is called “person-centered” care in MR/DD and “consumer-directed” care in aging (the former further along than

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<sup>4</sup> <http://www.lbo.state.oh.us/124ga/budget/RedbooksHouse/DMR/overview.htm>

<sup>5</sup> Factor, A., *et al*, (1997). *Planning for the Future: Aging Parents and their Adult Children*. Chicago: Rehabilitation Research and Training Center on Aging with Mental Retardation, University of Illinois at Chicago.

<sup>6</sup> Stone, R. (2000). *Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century*. New York: Milbank Memorial Fund.

<sup>7</sup> Arno, P.S., Levine, C., and Memmott, M.M. “The economic value of informal caregiving,” *Health Affairs*, Vol. 18, No. 2, 1999, 182-188.

<sup>8</sup> Applebaum, R. and Medizadeh, S. (2001) *Long-Term Care in Ohio: A Longitudinal Perspective*. Oxford, Ohio: Scripps Gerontology Center, Miami University.

<sup>9</sup> Fujiura, Glenn T. (1998) “Demography of family households,” *American Journal of Mental Retardation*, Vol. 103, No. 3, 225-235.

the latter). Each calls for increased autonomy for individuals, increased trust in their decision-making and self-care capacities, and increased flexibility in the use of public resources to meet individual and family needs.

The shift for which we now prepare is of a different sort than those experienced before. Earlier shifts were driven by changing sensibilities, ideologies and economics. The impending care shift is driven by demographics. It is less a movement than a collision of circumstances. Over the next decades, thousands of primary caregivers will die or otherwise lose their capacity to sustain care. Essentially, we are confronted with the gradual elimination of a giant program of volunteer workers, causing a significant cost shift.

The *cost shift* includes:

1. financial costs to federal, state, and county revenues
2. human resources costs in an already-limited pool of frontline workers
3. opportunity costs<sup>10</sup> to extended family members assuming new levels of care
4. quality-of-life costs to individuals with developmental disability whose routines and relationships have been displaced.

It should be noted at this point that while these costs are significant, it is not accurate or helpful to cast the care shift as a matter of loss only. In the best light, the shift of care, for example from living with a parent to living with age peers in a supported living arrangement, is an opportunity for development and variety over the life course. This requires the intersection of many factors, however, and has to be implied carefully; it simply cannot be promised in all situations, and net losses in quality of life have to be recognized when they are experienced as such.

It should also be noted that the care shift/cost shift will not be a two-step process, and does not affect only the MR/DD system. In many families, in-home aging network services may be needed by the aging caregiver(s) themselves and/or by age-eligible individuals with a developmental disability, even while the aging caregiver continues to provide housing, care, and support. Further complicating the picture is the interdependence evident in many of these families. Many able-bodied individuals with developmental disabilities provide instrumental support to their aging caregivers. Care is provided in both directions.<sup>11</sup> There is also evidence of financial reciprocity in many families.<sup>12</sup> Clearly, the care shift/cost shift is not simple and its course in individual families and as cohorts is not predictable. Even with these complexities, we

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<sup>10</sup> Birenbaum, A. and Cohen, H.J. (1993). "On the importance of helping families: Policy implications from a national study," *Mental Retardation*, Vol. 31, No. 2, 67-74.

<sup>11</sup> Hayden, M.F. and Heller, T. (1997) "Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation." *Mental Retardation*, Vol. 35, No. 5, 364-372.

Heller, T., Miller, A. and Factor, A. (1997) "Adults with mental retardation as supports to their parents: Effects on parental caregiving appraisal." *Mental Retardation*, Vol. 35, No. 5, 338-346.

Heller, T. and Factor, A. (1993) "Support Systems, Well-Being, and Placement Decision-Making Among Older Parents and Their Adult Children with Developmental Disabilities," in *Older Adults with Developmental Disabilities: Optimizing Choice and Change*, Sutton, E. et al, eds. Baltimore: Brookes Publishing Co.

<sup>12</sup> Heller, T. and Factor, A. (1988) Permanency planning for adults with mental retardation living with family caregivers. *American Journal on Mental Retardation*, 96, 163-176.

are left with the reality of an ultimate shift from primary informal to primary formal care of thousands of individuals with developmental disabilities in the State of Ohio.

### **Informal caregivers: Double Jeopardy families**

Double Jeopardy families are for the most part comprised of an aging parent or parents and one adult child with a developmental disability. Other family care arrangements also qualify; caregivers may be aging siblings, grandparents, aunts, or uncles. The unique qualifier is the aging of the families.

It is important in every discussion of today's Double Jeopardy families to be mindful of the cohort or generation they represent. The experience of this generation of caregivers is different from that of younger cohorts in a number of critical ways. First, as indicated earlier, parents who gave birth to a child with a developmental disability in the 1940s and 1950s, and even early 1960s, (or whose child acquired a disability during that time) had very few formal supports at their disposal. Professionals had only recently let go of the stigma-laden terms "idiot," "imbecile," and "moron" to classify levels of disability. When professionals recommended institutionalization, they contradicted the nurturing impulses of these parents; parents cared for their children in an atmosphere of shame and even blame. Rather than submitting to these isolating forces, parents coalesced and demanded services for their children. This generation of parents, in jeopardy today, was responsible for the first real system of home and community based services, for educational and work programs, and for recreational opportunities. The decisions and plans made by these parents on behalf of their adult children's futures cannot be fully understood without considering this history.

A second difference between this generation and their younger counterparts is the nature and size of their families. A generation ago, mothers were more likely to be homemakers (without working outside the home) and available to care for their children at home. They also had more children and therefore produced more potential for future sibling support than is possible in subsequent generations.

Today, aging families who care at home for individuals with a developmental disability have an array of services available to them. Even so, not all take advantage; those who do, do so in varying degrees. Of special interest are "hidden"<sup>13</sup> families," those unknown to the education or MR/DD systems. Hidden families become known most often in a crisis, upon the death or disability of the parent. Hidden families have coped without formal services and instead have relied on their own resources: kin, church, neighborhood, etc. They are of particular concern because they are hard to count; hidden families represent a significant problem in projecting the scope of the care shift. Hidden or known, families who have kept their adult children at home have saved the public billions of dollars. How many Double Jeopardy families are there in the state of Ohio?

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<sup>13</sup> Horne, M. (1989). Identifying a "hidden" population of older adults with mental handicap: Outreach in the U.K." Australia and New Zealand Journal of Developmental Disabilities, 15, 207-218.

### Chapter 3 SCOPE

As the state prepares for the care shift and budgets for the cost shift, reliable estimates related to Double Jeopardy families are important. Specifically, Ohio and its county boards need:

1. an estimate of services-eligible older individuals with MR/DD compared to the numbers known and served (including an accounting of waiting lists)
2. an estimate of those living with aging caregivers (60+) compared to the numbers known and served

Significant discrepancies exist between national experts' estimates of Ohio's aging MR/DD individuals and families and Ohio's own account of served individuals and families. The discrepancies suggest that Ohio is under-serving aging MR/DD individuals and families. Our challenge is to determine whether these discrepancies represent true gaps between need and services, or methodologies that produce either inflated prevalence estimates or deflated accounts of known and served individuals and families.

Arriving at estimates with confidence presents a number of challenges. First, discrepancies in definition and categorization create variable estimates. Second, state estimates extrapolated from national data sets (such as the U.S. Census and related surveys) cannot always account for state-to-state variation. Third, a time lag is imposed by the use of data gathered a decade ago (often the best data available); today's 60-year-olds are not the 60-year-olds of ten-year-old surveys. Fourth, data from surveys and programs are gathered through human reporting and documentation; this is an inherently imprecise process. Finally, needed data have not been gathered. Ohio has not gathered needed demographic data, such as caregiver ages. Ohio also lacks an organized, uniform system for maintaining and interpreting waiting lists.

Even with these limitations, we attempted to answer questions about the scope of Triple Jeopardy; where there are discrepancies, we identify contributing factors; where we lack needed data, we make recommendations for future data gathering.

#### *Data sources*

In arriving at estimates, we rely on a combination of the work of national experts and data gathered from Ohio's county boards. Key sources used by national experts include 2000 Census Bureau data (U.S. and Ohio); the National Health Interview Survey Disability Supplement (NHIS-D), a two-year (1994 and 1995) supplement that produced nationally representative data about non-institutionalized persons with disabilities; and the 1990 and 1991 samples of the Survey of Income and Program Participation (SIPP), a national household survey conducted by the U.S. Census Bureau.

Data gathered by county boards are limited in some critical ways. Most importantly, county board data are gathered from *known*, mostly *served*, individuals and families. Ohio does not have needed data about unknown, unserved individuals and families. Key sources used from county boards include the annual accounting of county board activity required by the Ohio Department of MR/DD (Individual Information Form, or IIF) and the Preliminary

Implementation Component Tool, or PICT. Both instruments gather and organize data about individuals served by county boards; PICT data are gathered to assist with fiscal planning for Medicaid waiver expansion and related refinancing of state and locally funded programs.

In this report, estimates of services-eligible individuals and families are produced by applying national prevalence estimates to Ohio census data. Accounts of served individuals are produced by county board data.

### *Prevalence rates*

From the NHIS-D, it is estimated that 4,132,878 individuals, or 1.58% of the U.S. population, have mental retardation (intellectual disability) and/or developmental disability.<sup>14</sup> The number living in non-institutional<sup>15</sup> settings is 3,887,158, or 1.49%. This estimate varies significantly by age, due to higher mortality in older ages and to differences in MR/DD definition across age groups.<sup>16</sup> Of the U.S. population in non-institutional settings, adults (19 and older) have a prevalence rate of .71%. The prevalence rate of children ages 0-5 years (3.8%) is nearly ten times the rate of adults 65 or older (0.4%). It is critical to account for differences in prevalence rates when studying --- and planning for--- older cohorts.

For purposes of policy and program planning, it is also important to distinguish services-eligible individuals from individuals with disabilities who would be ineligible for services under current criteria. Mental retardation and developmental disability are neither interchangeable nor mutually exclusive categories. In the adult non-institutionalized population, 40% have developmental disability and mental retardation, 34% have a developmental disability and no mental retardation, and 26% have mental retardation but no developmental disability.<sup>17</sup> In general, adults falling into the last category do not meet eligibility criteria for MR/DD services in Ohio. Therefore, in most of our calculations we adjust for that ineligible 26% by multiplying estimates by .74.

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<sup>14</sup> Larson, S., Lakin, C., Anderson, L., Kwak, N., Lee, J.H., Anderson, D. "Prevalence of Mental retardation and/or developmental disabilities: Analysis of the 1994/1995 NHIS-D", MR/DD Data Brief, April 2000, Volume 2, Number 1.

<sup>15</sup> Larson, S., Lakin, C., Anderson, L. and Kwak, N. 2001. "Demographic Characteristics of Persons with MR/DD Living in Their Own Home or with Family Members: NHIS-D Analysis", MR/DD Data Brief (University of Minnesota, Institute on Community Integration), Vol. 3, No. 2. In these estimates, "institutional" settings are those with four or more residents. The language is problematic, and it should be noted that Braddock, *et al* (p. 2) (See note #) describe settings of six or fewer as "family-scale settings."

<sup>16</sup> According to Larson, Lakin, Anderson, and Kwak ("Demographic Characteristics of Persons with MR/DD Living in Their Own Home or with Family Members: NHIS-D Analysis", Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, June 2001, Vol. 3, No. 2.), "A small part of [age variability in prevalence rates based upon a non-institutional sample] is likely attributable to the increasing likelihood of 'institutionalization' as individuals move through adulthood...But given the relatively small ratio of institutionalized to noninstitutionalized adults, most of the variability observed must be due to other factors." (p. 14) Our figures (See Table 2) suggest that the ratio of institutionalized to noninstitutionalized is not so small.

<sup>17</sup> These proportions are significantly different for younger ages, due to differences in definition for younger cohorts.

Using year 2000 Ohio Census data, Table 2 applies age-specific prevalence rates in the non-institutionalized population and adds known numbers living in “institutional” ( $\geq 4$ ) settings to arrive at estimates of eligible individuals age 30+, in five-year cohorts.

**Chapter 4 How many Ohio residents are eligible for MR/DD services? How many are served? Unserved?**

Table 1 provides the numbers of Ohio individuals served by the MR/DD system, categorized by age and setting. Table 2 provides: 1) an estimate of eligible individuals in five-year cohorts, age 30 and older; 2) the known number served in each of those cohorts (from Table 1); 3) the difference, or the estimated number unserved. Not all unserved individuals and families are unknown to the system. They may have used and discontinued services; they may have gone through an intake process without accepting services; they may be waiting for preferred services. Those unknown to the system are “hidden” families. We must regard the estimated number of unserved as a combination of these categories. Because county boards do not keep data on the unserved who are also known to the system, we cannot estimate how many are unknown to the system.

**Table 1. Ohio numbers served by age and setting**

Age Group	Own place no SL	With family	Foster	Group home	ICFMR	DC	NF	Other	Unknown	SL or IOW	Total
Under 30	746	28,898	1,329	471	881	99	85	207	116	689	33,521
30 to 34	442	2,047	72	320	535	92	40	40	8	557	4,153
35 to 39	440	1,914	75	406	685	141	79	33	11	610	4,394
40 to 44	540	1,792	76	503	810	189	86	46	10	706	4,758
45 to 49	452	1,407	66	504	818	213	111	29	7	629	4,236
50 to 54	376	929	66	487	708	146	153	35	6	532	3,438
55 to 59	232	525	39	406	466	113	160	17	5	408	2,371
60 to 64	160	268	27	265	347	50	174	20	5	273	1,589
65+	208	233	64	417	592	88	633	42	3	397	2,677
Total	3,596	38,013	1,814	3,779	5,842	1,131	1,521	469	171	4,801	61,137
30+	2,850	9,115	485	3,308	4,961	1,032	1,436	262	55	4,112	27,616
40+	1,968	5,154	338	2,582	3,741	799	1,317	189	36	2,945	19,069

Chapter 5 SL (Supported Living); ICFMR (Intermediate Care Facility-Mental Retardation); DC (Developmental Center); NF (nursing facility); IOW (Individual Options Waiver)

**Table 2. Prevalence estimates and estimated unserved**

Age Group	Ohio population <sup>18</sup>	Prevalence rate <sup>19</sup> (noninstitutionalized) X .74	Estimated # non-instit.	Known # instit. <sup>20</sup>	Total estimated # eligible (est. non-instit. plus known instit.)	Number served <sup>21</sup>	Estimated unserved
30-34 and	781,225	(.008 X .74) .00592	4,625	987	5,612	4,153	1,459
35-39	905,565	(.008 X .74) .00592	5,367	1,311	6,678	4,394	2,284
40-44 and	898,751	(.007 X .74) .00518	4,656	1,588	6,244	4,758	1,486
45-49	834,893	(.007 X .74) .00518	4,325	1,646	5,971	4,236	1,735
50-54 and	731,501	(.005 X .74) .00370	2,707	1,494	4,201	3,438	763
55-59	553,174	(.005 X .74) .00370	2,047	1,145	3,192	2,371	821
60-64	455,732	(.005 X .74) .00370	1,686	836	2,522	1,589	933
65+	1,507,757	(.004 X .74) .00296	4,463	1,730	6,193	2,677	3,516
Total 30+			29,876	10,737	40,613	27,616	12,997
Total 40+			19,884	8,439	28,323	19,069	9,254

<sup>18</sup> U.S. Census Bureau, 2000. The Ohio census is organized in 5-year cohorts with the exception of five 10-year cohorts: 25-34, 35-44, 45-54, 65-74, 75-84, and one open cohort, 85+. To arrive at 5-year cohorts in needed age groups, we split the 10-year cohorts according to proportions of 5-year cohorts from the Intercensal Estimates of the United States Resident Population .

<sup>19</sup> Prevalence rates by age group, for non-institutionalized population, from Larson, Lakin, Anderson, and Kwak , 2001 (“Institutional” settings = settings of ≥4 individuals.)

<sup>20</sup> These figures are from group home, ICFMR, developmental center, and nursing facility IIF data. following the definition of “institutional” used by Larson, Lakin, Anderson, and Kwak, 2001. This approach excludes individuals in foster care, supported living, or individual options waiver who live in settings of 4+.

<sup>21</sup> See Table 1.

## **Chapter 6 What is the number of eligible individuals with a developmental disability age 60 and older?**

*These individuals are dealing with their developmental disabilities and their own aging. They have reached the age of eligibility for aging network (Older Americans Act) services.*

One approach to estimating this number is the “rule of thumb” approach recommended by Matthew Janicki<sup>22</sup>. The rule of thumb is 4/1000 persons ages 60+ in a geographic area. Applying this rule of thumb to the 2000 Ohio census (1,963,489 Ohioans age 60+), produces an estimate of 7,854 individuals with MR/DD and 5,812 *eligible* individuals (7,854 X .74) age 60+ living in Ohio.

A second approach recommended by Janicki is to multiply the number of individuals age 60+ in the state’s registry census (4,266) (See Table 2, “number served”) by a factor of two (= 8,512) to four (= 17,064).

A third approach is to use prevalence rates by age group derived from NHIS-D data (Table 2) and multiplied by .74 to include eligible individuals only. Because NHIS-D data exclude individuals in institutional settings, we add this known number to the estimates. Using this approach, we estimate 8,715 eligible individuals age 60+.

Thus we are confronted with a wide range of estimates of the number of eligible individuals with a developmental disability age 60 and older: from a low of 5,812 to a high of 17,064. Two of the approaches produce estimates at mid-range: 8,512 (number served times a factor of two) or 8,715 (using rates from NHIS-D data). We are comfortable with the NHIS-D estimate of **8,715** individuals in this category.

### **What is the number eligible 60 and older unserved?**

IIF data indicate that 4,266 individuals age 60+ are served by county boards; only 501 of these served individuals live with family. Using the NHIS-D based estimate (8,715 eligible individuals age 60+), we conclude that 4,449 of individuals age 60 and older are unserved. Is it possible that a sizable number of these individuals is being accommodated by nursing homes or related settings outside and unknown to the MR/DD system? Or are they living with siblings or other family? This is clearly a question for further study.

## **Chapter 7 What is the number of eligible individuals with a developmental disability ages 40 to 59? How many of them are served? Unserved?**

*These are individuals at especially high risk of living in Double Jeopardy families today.*

We estimate that there are 19,608 eligible individuals age 40 –59. Ohio data indicate that 14,803 of that estimated number are served, and 4,653 of those served are living with family. We estimate that 4,805 of individuals ages 40-59 are unserved. We assume that most unserved eligible individuals in this age group live with family.

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<sup>22</sup> Janicki, M.P. “Coordinating Systems Serving Carers of Children and Adults with Developmental Disabilities” RRTC on Aging with Developmental Disabilities, Volume 4, November 25, 2001. Item: 600.006.

**Chapter 8 What is the number of eligible individuals with a developmental disability ages 30 to 39? How many of them are served? Unserved?**

*These are individuals at some risk of living in Double Jeopardy families today, and at high risk ten years from now.*

We estimate that there are 12,290 eligible individuals age 30 –39. Ohio data indicate that 8,547 of that estimated number are served, and 3,961 of those served are living with family. We estimate that 3,743 of individuals ages 30-39 are unserved. Again, we assume that most unserved eligible individuals in this age group live with family.

**Chapter 9 What is the number of services-eligible individuals living with aging caregivers (60+)?**

*These are individuals at risk of losing their informal care arrangement, due to death or disability of the aging caregiver; they live in Double Jeopardy families.*

This estimate is more difficult than broad prevalence estimates, particularly because we would expect state-specific characteristics (available services, aging of population) to affect the likelihood of this arrangement. The question addresses an area of significant discrepancy between the estimates of national experts and Ohio’s own data. Using SIPP data, Fujiura<sup>23</sup> estimates that, nationally, 456,600 or 25% of individuals with MR/DD living with caregivers, live with a caregiver age 60+. Using these data, David Braddock and colleagues, in their 2002 *Summary of State of the States in Developmental Disabilities*<sup>24</sup>, estimate the number of Ohio individuals with developmental disabilities living in households with caregivers age 60+ is 29,318. Correcting for eligible individuals (.74), the estimate is 21,695. Braddock and colleagues’ estimate is based upon a prevalence rate of 1.58% (both institutional and non-institutional settings), and uses the Ohio population, Ohio’s out-of-home placement rates, and Fujiura’s SIPP national estimates of the numbers of individuals living in households with aging caregivers to arrive at Ohio’s estimate. (See Appendix A)

Currently, Ohio serves 9,115 individuals age 30 and older and 5,154 individuals age 40 and older who are living with family (Table 1). If the Braddock estimate is on target, the number of Double Jeopardy families is more than double number of those families we know and serve, even if all 9,115 individuals age 30+ living with families lived with caregivers age 60+. We made several attempts, from many angles, to respond to this discrepancy with existing Ohio data, but the available information is simply inadequate. In recent efforts<sup>25</sup>, Ohio has inferred the presence of aging caregivers from the age of individuals with MR/DD living with family, using age 40 as a point of inference. We have two indicators that this approach is problematic. First, according to Fujiura (1998), the average age of individuals living with a caregiver 60+ is 38.4. Although it is possible that the mean is skewed by young grandchildren cared for by grandparents, the mean still suggests that we should pay more attention to cohorts under age 40.

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<sup>23</sup> Fujiura, G.T. “Demography of Family Households,” *American Journal of Mental Retardation*, 1998, Vo. 103, No. 3, 225-235.

<sup>24</sup> Braddock, D., Hemp, R., Rizzolo, M.C., Parish, S. and Pomeranz, A. *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities and Department of Psychiatry, The University of Colorado, 2002.

<sup>25</sup> Communications among Leah Holden (ODMRDD), Elsie Helsel (ODDC), and Carol Shkolnik, (ODA). See also: *Ohio Access for People with Disabilities*, Final Report to Governor Taft, 2001.

(This was part of our rationale to include 30-39-year-olds in Tables 1 and 2) Second, PICT data<sup>26</sup> suggest that *not all age 40+ individuals living with family live with caregivers 60+, and a significant number living with caregivers age 60+ are under age 40*. Our simple inferences won't work. Until Ohio asks the caregiver age of all served individuals living with family, we will not have data necessary to understand the discrepancies between the Braddock estimates and Ohio's own estimates. Even then, we will only have data on served individuals with which to respond. How can we understand the scope of Ohio's hidden Double Jeopardy families?

**What is the number of hidden families with caregivers age 60+? (How many of the unserved are also unknown to us?)**

Clearly, because without additional data, we cannot know the number of served individuals living with caregivers age 60+, it is not possible to estimate the number of hidden families in this category. Subtracting the total number (9,115) of served individuals age 30+ living with family (assuming for the sake of argument that all live with caregivers age 60+) from Braddock, et al, estimates of Ohio eligible individuals living with a caregivers 60+ (21,965), suggests that Ohio is not serving approximately 12,850 eligible individuals living in Double Jeopardy families. Because we know that not all individuals age 30+ live with caregivers age 60+, we must regard this as an underestimate. As stated earlier, we cannot know how many of the unserved are also unknown, because Ohio does not keep data organized to answer that question.

What should we make of such a dramatic discrepancy? Braddock's figures are alarming, and they are also the best we can work with at this time. It can be helpful to look at a study conducted in New York state. Janicki, et al (1998) conducted a New York demonstration project that involved Area Agencies on Aging in outreach and direct service to aging families caring for a member with a developmental disability. The outreach process produced a striking statistic: only 54% of the qualifying families identified in the Area Agency on Aging outreach process were also known to the state's MR/DD system. Forty-five percent were hidden families. Although we cannot assume that Ohio's situation is similar, we have few reasons to argue that it is dissimilar. This proportion of hidden families, if held true in Ohio, lends support to Braddock's estimates; it suggests a larger Double Jeopardy population and a more complex Triple Jeopardy challenge.

On the other hand, Ohio's recent experience, at least anecdotally, has not produced a deluge of once-hidden families seeking services, even though the first of the baby boomers' parents are in high-risk ages for disability and mortality (mid seventies and early eighties). Hidden Double Jeopardy families of baby boomers, if they are going to come out of the woodwork, should have started to do so by now. The experience we have with the earliest cohorts of baby boomers' families should tell us at least something about the proportions of hidden and known families in later cohorts. Ohio must begin to gather and organize data, county by county, to document the

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<sup>26</sup> Until very recently, Ohio's county boards did not collect data about the age of caregivers of served individuals living at home. As of October 2001, PICT instruments ask the question: "Living with a caregiver 60+?" PICT data are gathered to assist with fiscal planning and represent individuals anticipated to enroll on a HCBS waiver. It must be noted that this question only targets known and served individuals and families; those unknown and/or unserved are excluded from this measure. We have PICT data on 4,872 out of a total of 61,137 served individuals. Although it is tempting to use PICT data to interpret the scope of Double Jeopardy, we cannot assume that the PICT population is representative of the total served population.

numbers of once-hidden families who become known to the system when informal care breaks down. This accounting may be one of our best predictors of the care shift.

A reminder is crucial at this point. It is not only the hidden Double Jeopardy families that are of concern to us. *All* Double Jeopardy families, both hidden *and* served, are at risk. Once the informal (family) care arrangement breaks down, hidden individuals will need services perhaps for the first time, and most served individuals will become dependent on the formal system for their care and support.

### **Waiting list issues**

In the best of all worlds, waiting lists for services would be a meaningful indicator of need and demand for those services. Unfortunately, as stated earlier, Ohio counties lack a uniform, systematic approach to organizing and maintaining waiting lists for services. And, because the demand for services usually far exceeds their availability, crisis-point (emergency) services may consume all available slots. This leaves the waiting list to shift without moving forward as more people are added.

Understanding the scope of current unmet demand for services is essential to understanding the scope and future impact of Triple Jeopardy. Because of limited available data, we were not able to address the scope of the waiting list issue.

### **Chapter 10 What we do know about the scope of Double Jeopardy?**

Although there is much we cannot know about the scope of Double Jeopardy given limited available data, we do know the following:

- Ohio has a waiting list problem; we are unable to meet existing demands for services, particularly residential care.
- We estimate that there are 8,715 eligible individuals age 60 and older, dealing with their own aging in addition to (and sometimes complicating) their developmental disabilities. An estimated 4,449 of those individuals are unserved by county boards. We do not know whether they are receiving care from siblings or other family, or through formal care systems other than MR/DD.
- We know that there are 3,961 served individuals ages 30-39 living with family and an estimated 3,743 unserved eligible individuals most of whom are assumed to be living with family; this age group is at risk of loss of informal care today and especially high risk one decade from now.
- We know that there are 4,653 served individuals ages 40-59 living with family and an estimated 4,805 unserved eligible individuals most of whom are assumed to be living with family, at especially high risk of loss of informal care today.

- Until we have Ohio data to argue otherwise, we must acknowledge the possibility of a significant number of hidden families, suggested by Braddock's estimates of Ohio's individuals living with caregivers age 60+ (21,695 eligible individuals).

## **Chapter 11 Estimating the Value of Informal Care**

We can provide a broad estimate of the value of the care provided in Double Jeopardy families. The Legislative Budget Office (2001) calculates the average annual cost per Residential Facilities Waiver recipient at \$27,763. Individual Options Waiver recipient costs average \$36,247., and ICF/MR care averages \$65,000. Multiplying the most conservative figure (\$27,763) times the 21,695 Double Jeopardy families estimated by Braddock, produces an annual value of informal care at \$602,318,285. This estimate does not account for the value of services currently received by these families and individuals, but in using the most conservative of the figures, we compensate for this problem in part. We advise caution in using this estimate, particularly given the observation that an anticipated first wave of Double Jeopardy families in crisis has not materialized to the extent that Braddock's figures would predict.

## **Chapter 12 ABSORBING THE CARE SHIFT: THE FORMAL SYSTEM**

How ready is the formal system of services to absorb the care shift? Ohio is not meeting *current* demand for services, but a recent reorganization of services has expanded their availability. Broadly, state-funded, county-board-administered MR/DD services to adults are organized to provide: 1) support to families caring for individuals with MR/DD, 2) support to individuals to live in independent or family-scale settings outside their own family, and 3) care in ICF/MRs (Intermediate Care Facilities-Mental Retardation) and developmental centers. Nearly all county boards supplement their budgets through local tax levies. As stated earlier, there are over 6,500 individuals on waiting lists for services (Ohio Office of Budget and Management, 2001). In an effort to close the gap between demand and available services, Ohio entered into a comprehensive system redesign of services through legislation enacted in 2001.

### **Chapter 13**

### **Chapter 14 System Redesign**

An increasing source of funding is the leveraging of federal funds through Medicaid Home and Community Based Services (HCBS) Waivers. Waiver programs match state funds with federal dollars. Waiver-funded support expanded nearly ten-fold in the 1990s, from serving 420 individuals in 1992 to 4,093 in 1998. Nevertheless, in Fiscal Year 2000, Ohio ranked fortieth among states in federal HCBS waiver expenditures as a percentage of total (MR/DD) spending.<sup>27</sup> Ohio ranked fourth in the percent of state funds potentially available, but untapped, for federal match.<sup>28</sup> In response to this lapse, the Ohio Budget enacted in 2001 (House Bill 94) redesigned the Medicaid system for MR/DD, allowing the use of local levy dollars for federal match and expanding Medicaid waiver slots by at least 500 each year. The system redesign increases the total dollars available to meet demand for services. The redesign also includes a priority

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<sup>27</sup> Braddock, et al, (2002) *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities and Department of Psychiatry, The University of Colorado.

<sup>28</sup> *Ibid.*

enrollment strategy, and individuals living with caregivers age 60 and older have been designated a priority enrollment group. Ohio's goal is to serve an additional 20,000 individuals through the redistribution of dollars over the five-year Medicaid Waiver agreement period.<sup>29</sup>

System redesign also includes the technical restructuring of old waivers and the establishment of new ones. The Residential Facility Waiver and Individual Options (IO) Waiver are merged, Supported Living individuals are targeted to the IO Waiver, and Family Support individuals are targeted to a new Basic Support Waiver. Essentially, three county board operated programs (Adult Day Habilitation, Family Support, and Supported Living Services), all previously funded through state and local dollars, will be shifted to HCBS Waiver funding for federal match.

Chapter 15 System redesign improves the hope of support for Double Jeopardy families, and reduces Ohio's state of Triple Jeopardy to some degree. Even so, demand for waiver slots will continue to exceed their availability. Furthermore, critical issues, such as the shortage of qualified direct care workers and the shortage of housing, are not resolved by merely expanding dollars to pay for services. The HB 94 budget earmarks funds for the recruitment and retention of direct care staff, an important component of system redesign.

### **Chapter 16 Aging-MR/DD-ODDC Collaboration**

The last few years have seen progress in aging-MR/DD collaboration at the federal and state levels. The Older Americans Act (OAA) requires collaboration between aging network services (state units and area agencies on aging) and state and local (county) MR/DD agencies. The 2000 OAA amendments also mandate special assistance to caregivers who provide uncompensated care for individuals with developmental disabilities, through the Family Caregiver Support initiative<sup>30</sup>.

In Ohio, a November 1999, a Memorandum of Understanding between the Ohio Department of Aging and the Ohio Department of MR/DD was signed by the departments' two directors. It was reaffirmed and re-signed in 2001. The agreement outlines collaborative approaches to meeting the needs of Double Jeopardy families. Representatives from the two agencies meet regularly to develop inter-agency strategies for meeting shared objectives.

The Double Jeopardy project, developed with grants from the Administration on Developmental Disabilities, is the most visible example of inter-agency activity. It involves the Ohio Department of Aging as the lead agency, and includes the Ohio Department of MR/DD and the Ohio Developmental Disabilities Council (ODDC). The Double Jeopardy project has two levels of goals. "The macro level goal...is to expand and enhance a family-centered and family-directed, culturally competent, community centered, comprehensive system of family support that will ultimately be available statewide. The micro-level goal is to support families in planning for a secure future for the aging family member with a developmental disability as well as the aging [caregiver]." (Ohio Department of Aging, p.ii)

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<sup>29</sup>Ohio Department of MR/DD, Concept Paper to CMS for Ohio MR/DD System Redesign

<sup>30</sup> <http://www.aoa.gov/Oaa/2000/PL106-501.html>

The Double Jeopardy project seeks to meet the long-term care needs of Double Jeopardy families; it also promotes and supports family decision making and planning for the future needs of individuals with developmental disabilities. State-wide discussions and inter-agency collaboration are increasing, and are sure to have an impact on the state of Triple Jeopardy.

### **CARE SHIFT – COST SHIFT: THE HUMAN FACE**

Too frequently, we talk and write about families such as “Double Jeopardy” families as though we can understand and explain them with one label. Preparing effectively for the care shift requires understanding its complexities. In an effort to get at the diversity of this population, we used two qualitative methods: participant observation and semi-structured interviews. This is an exploratory approach that contributes to our understanding of the idiosyncratic experiences of families, the dynamics of the care shift/cost shift, and our interpretation and use of demographic and other quantitative data.

We conducted twelve case studies (day-long, in-home family visits) with the following objectives:

1. to put a human face on the “numbers”
2. to shed light on the complexities of family circumstances
3. to illustrate the economic value of care provided by parents (and its relation to the impending cost shift)
4. to demonstrate the inevitability and imminence of the care shift
5. to identify anticipated issues in facilitating a successful care shift

#### *Sample*

In a qualitative project such as this, sampling is conducted to cover characteristics and demographics important to the exploration. Generalizability is not an objective; that is, we did not set out to identify a sample representative of all Ohio Double Jeopardy families. Instead, we selected twelve families to include (but not represent) a range of family compositions, ages, racial and ethnic backgrounds, socioeconomic status, geography, and nature and level of care.

We solicited the help of county boards in identifying and recruiting families (caregivers 60+, caring for an individual of unspecified age in the same household) for participation in the project. We identified participating families one at a time, filling needed categories as the project progressed.

The 12-family sample actually includes thirteen individuals with a developmental disability (one family has two children with a disability). Six of the thirteen are female. Ages range from 27 to 58. (Seven are in their forties.) Broadly, seven of the sample have a high level of disability, three have a moderate level, and three are relatively high functioning. Disabilities include mental retardation (intellectual disability), cerebral palsy, autism, epilepsy, and brain injury. Some have chronic medical conditions, including diabetes and stroke. All family caregivers in the sample are parents. Six are single-parented families, either widowed or divorced; one family includes a

domestic partner; five include both parents. Parents' ages range from 66 to 86. Three families have caregivers in their eighties, seven in their seventies, and two in their sixties. Two families are African-American, and ten are Caucasian. Four families live in a rural setting, four in a suburban setting, two in small towns, and two in urban areas. A wide range of socioeconomic status is included; some parents qualify for Medicaid themselves. The sample includes a continuum of sibling involvement, from no living siblings to a sibling who lives in a connected apartment.

### *Data Gathering*

Each family was visited by one of two researchers. In most cases, the researcher arrived as morning preparations were underway and departed sometime in the evening. The researchers were "on site" as early as 6:30 a.m. Families were asked to go about their usual daily routines. The researchers took notes, made observations, and asked questions when appropriate. In every case, an extended interview (90 minutes or more) was also included. In five cases, the researchers spent a small part of the day observing the individual with a developmental disability at his or her work place. All families were visited on weekdays, when formal supports were more likely to be "in action." Information about weekend routines was gathered in the interviews. Observed and reported caregiving activities were recorded, as were self-care behaviors.

### *Data Analysis*

Notes from observations and interviews were coded and themes identified. Caregiving activities and self-care capacity were organized to establish a profile of the level of care needed and provided in the household, including mutual help (parent to child and child to parent). Using these profiles, the researchers met with a representative from the county board (usually an emergency placement coordinator) in each family's community, to establish an economic value of the family care provided. The economic value of family care was generally based on the projected cost to the state and county of a formal care arrangement in the absence of family support. Board professionals provided a figure or range of figures as "best estimates" without the benefit of an actual intake assessment.

## **Chapter 17 TWELVE FAMILY PROFILES**

### **The Richardson<sup>31</sup> Family Rural setting**

**Nell and Ben, ages 68 and 75**  
**Chapter 18 Son Kenneth, age 43**

The “day” in the Richardson family actually began somewhere in the middle of the night when Kenneth’s body hit the alarm pad at the side of his bed downstairs, alerting his parents that he was having a seizure, a near-nightly occurrence. It is Nell’s time to get up and tend to him, and Ben will take his turn when the alarm pad goes off again at 5:45 a.m., Kenneth’s usual rising time. Kenneth is a big, good-looking bearded man, about 6’7” and 240 pounds, who was born without problems but had a life-changing reaction to a DPT shot at age 6 months. He can only remember emotional experiences and can retain very little learned information. Kenneth can converse, though he’s prone to perseveration, and has poor judgement and attention. He walks with a wheeled walker and supervision, and any walks outside the home require shin pads and a helmet. (He has broken his leg twice in falls, and his walking must be supervised.)

Ben’s first wife and Kenneth’s mother died in 1967. This is a second marriage for both Nell and Ben, who were married in 1971. Nell has a daughter with autism who lives with her first husband. Between them, Ben and Nell have four other children, all of whom live several states away. The family moved to Ohio from the West Coast just a few years ago. Kenneth spent sixteen years in an institution there, coming home three nights each week. Until rather recently, Kenneth’s violent behavior was very difficult to manage. Ben describes Kenneth as “mellowed somewhat.” As soon as the Richardsons were able to manage Kenneth sufficiently, they brought him home full time. The quality of care at the institution had deteriorated; even so, Ben and Nell believe that well-implemented institutional care can be an appropriate fit for someone with Kenneth’s needs. They had hoped that he could move into one of Ohio’s developmental centers that care for individuals with epilepsy. They have been disappointed to find this arrangement closed to Kenneth.

Kenneth has gotten himself dressed this morning. In a sunny kitchen with a gallery of family photos, Nell has fixed breakfast --- omelet, toast, and juice--- which Ben takes to Kenneth’s room while Nell showers. Turn taking is part of the family routine; because of Kenneth’s seizures, he cannot be out of earshot. When Nell is finished showering, it’s Ben’s turn; he will keep his ears “tuned in” from the next room. After breakfast, Kenneth watches TV and puts a Christmas album (it’s early May) on his turntable, both at equal volume. Kenneth’s room is neat and orderly and he makes his bed with great effort and tenacity. In a while, Ben comes in with the first of five daily doses of Kenneth’s medications and vitamins. Though Kenneth can make his way to the bathroom and do most of his toileting, he needs help with hygiene afterward; this is Ben’s job. It is almost time for Lisa, one of 3 companions hired by the Richardsons, to arrive. Formerly a waitress, Lisa had shown kindness to Kenneth and his family, her regular customers. Though Lisa had no related experience the Richardson’s enticed Lisa to work for them, and she has been with them for six months.

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<sup>31</sup> In all family profiles, names and other identifying information have been changed.

Today, during Lisa's "watch," Ben and Nell go to breakfast with friends, Ben keeps an appointment to work out some legal/financial arrangements, and Nell makes a two-hour drive to the family dentist (the only one they've found willing and able to work with Kenneth). Once home from his appointment, Ben will steal some quiet time in his study to work on a book he has been writing. Kenneth, meanwhile, spends nearly 3 hours (literally) sawing logs in the back yard. Kenneth's passion for log sawing was discovered serendipitously during some lawn clearing. Now Kenneth spends a few hours every day seated in front of a homemade sawhorse designed to accept what seems to be a limitless supply of small tree branches. He saws away untiringly and ultimately fills four large cardboard boxes, stopping only for the lunch that Nell has prepared ahead of time. The lunch of vegetable soup and the colorful vegetable salad are part of the diet that has dropped 70 pounds off Kenneth's frame and improved his walking. When the day's supply of wood has been sawn, Kenneth and Lisa take a walk to retrieve the mail, another daily routine.

After Lisa has left and Nell has returned from her five-hour journey to and from the dentist, the family goes to dinner at Kenneth's favorite restaurant, a weekly outing. For this trip, Kenneth uses a wheelchair, the family goes early, and the restaurant has a table waiting. Kenneth must be coaxed to eat slowly, and his behavior is closely monitored. Aside from seizures, Kenneth is prone to rages, and at least once the family has made an early exit from the restaurant. After dinner, Nell is off to a church function meeting, and Ben retreats for more writing, but always within earshot of Kenneth. Ben says that this has been an uncommonly good day: no daytime seizures, no falls, no rages. Bedtime comes quietly at nine o'clock. The alarm pad will sound in a few short hours.

By the time Kenneth turned 21, the Richardsons had spent \$150,000 on his care out-of-pocket. Since 1998 the Richardsons have had a lifetime trust at their disposal for Kenneth's care --- approximately \$100,000 annually from a class-action lawsuit related to his DPT shot. The Richardsons are somewhat unusual because they are financially compensated ---in part--- for Kenneth's care. Ben takes a court-approved "wage" of \$4.00 per hour from the trust; this is then applied toward the mortgage and other expenses of the home they all share. The Richardsons pay Lisa \$10 an hour. The other caregivers are "agency" caregivers and cost \$13-15 an hour. Even with their resources, the Richardsons have not been able to find an adequate number of suitable caregivers to provide the amount of care they would like for Kenneth. As a family, they are short-staffed, and this is an on-going problem.

**Value of Informal Care:** Computing the value of informal care in this family is more complicated than most, because of the unusual level of private financial resources accessible for Kenneth's care. These resources make him ineligible for waiver programs. Kenneth's seizures, gait problems, and behavior problems add to the costs of his care. His county board estimates that Kenneth's care would cost approximately \$116,000 annually; if he is able to live with another individual, the cost might be reduced by a third to not quite one half of that amount. This does not include housing, groceries, transportation and other living expenses. Kenneth's trust and his Social Security have the potential to cover his costs if he is able to live with others. If he is not, public funds will be required to supplement the costs of his care.

**The Future:** If and when Nell and Ben are no longer able to care for Kenneth, the trust will be managed by a family member. Clearly, this trust will significantly relieve the public "burden." There is no expectation that his siblings or step-siblings care for Kenneth at any time in the

future, except to manage his trust. The Richardsons have been active in Voice of the Retarded, an organization that advocates for a full range of housing and care options, including institutional care. Denied this option, Nell and Ben are exploring the possibility of establishing a Camphill community at their rural home. Camphill communities (established in Europe in the 1930s) are communal settings founded on a set of social ideals that incorporate the inclusion and nurture of individuals with developmental disabilities. Meanwhile, it is clear that, as it now stands, Kenneth's care requires both parents; should something happen to either one of them, increased in-home services or out-of-home placement would become immediately necessary.

### **The Stevens Family Suburban setting**

**At home:  
Kate and Clark, ages 71 and 72  
Son Bill, age 44**

Bill has jet-black hair and eyebrows and a balding pate. His 5'10", 190-pound build is diminished somewhat by rounded shoulders and a slightly bowed head. At 7:45 a.m., Bill, who has autism, and his mother Kate sit on the tree-shaded bench at the end of their driveway, waiting for the bus that will take him to his workshop. He has had a "sink bath" with his dad's help; Kate has brushed and flossed his teeth, and shaved him. He has dressed himself and eaten breakfast, prepared by Kate. Bill does all this silently. Although he understands language and can read, he is unable to express himself, with the exception of several mumbled words understood by his parents and professionals who work with him. According to his mother, Bill "has never once cried." When the bus arrives, Bill accepts a peck on the cheek from his mom, and returns a peck on her request. This kiss from him is hugely important, a "miracle," because after 44 years, it is a recent occurrence in this family. It is one of what Kate calls "Bill-isms," or new signs of personality and emotion that are connecting him to his parents and potentially to others. Says Kate, "We are just getting to know him."

Bill was parent tutored through extensive training from an Autism Research Program, and this was supplemented by minimal home tutoring from the public school system until age 22. He had very little away-from-home experience before he started with the county-run sheltered workshop at age 22. Bill's workshop is suffering from the same economic downturn faced by other businesses these days. There is simply no work for Bill to do today, and he spends his hours at his workstation completing a complex jigsaw puzzle. Bill has an uncanny talent with puzzles and seems quite content with this solitary project. Bill relates little to others, but he indicates a particular attachment to his supervisor at the workshop. He also enjoys a Sunday school class designed for adults with developmental disabilities at his church. Bill participates in a board-sponsored weekly social night, although he does not attend events such as dances that are highly interactive. Kate and Clark call the workshop a "blessing," for both Bill and themselves. They tell of the awe with which they regard the fact that after having Bill at home full time until age 22, someone actually comes to their home, picks him up, gives him something to do for a whole day, and returns him to their doorstep. This is a tremendous source of respite to Kate and Clark, who have been each other's respite all these years, "spelling" each other for precious time away. Kate takes time for her professional art, and Clark golfs when he can,

regularly on Tuesdays. Friends have fallen or moved away over the years, and Kate and Clark rely heavily on each other for a social life. Even so, Clark says, "It's lonely."

Kate and Clark feel especially alone since the death of their only other child, a daughter, two years ago. Although she had moved across the country, it was this daughter who was to serve as Bill's guardian upon her parents' deaths. Instead, Kate and Clark nursed her in her last months of life; as Kate describes it, this was a cherished time of caring for a daughter who, for most of her life, had taken a back seat to her brother's needs. Now, in the middle of their grief, Bill has their full attention.

Bill takes medicines for high blood pressure and seizures; the seizures began in puberty and are fairly well under control. He has obsessive-compulsive tendencies that are well handled without medications. Bill's most recent obsession is with words, and Kate is putting this to use. When Bill arrives home at 4:15, Kate and Clark warmly welcome him, but he heads straight to what is best described as his classroom in a corner of the family room. Kate is determined to uncover the way to link Bill's understanding of written words---mostly nouns, some verbs, a few adjectives---- and his limited ability to pronounce them, to a spontaneous *use* of those words to express himself and connect through language to the world around him. In this classroom full of workbooks, charts, books, papers, pencils, tape recorders, and music, Bill and Kate work: Bill, the deliberate student, and Kate, the eager teacher. Bill fills in workbook sheets, Kate reviews and "corrects," and Kate reads stories. There is much praise, and Bill indicates satisfaction. After an hour or so, school is out, and Kate prepares dinner.

Dinner is at 7 pm. The family says grace and Clark and Kate talk and eat, while Bill concentrates on his meal. During dinner Bill pulls out his wallet and hands his father his paycheck from the workshop. Again there is much praise. When dinner is over, the family watches television together. Bedtime is 10 o'clock. Kate and Clark help with evening washing and teeth brushing. Bill sleeps in an orderly room that his autism keeps him from disturbing. His parents would welcome a mess in there.

**Value of Informal Care: \$50,205 per year** (3 roommates, awake overnight staff, no staff during workshop, 16 hours extra "reserve" each month, transportation costs, extra 1:1 staff for Bill only, on weekends)

### **The Future:**

Kate and Clark call themselves "ALAPs" ---- "as long as possibles"---- meaning that they want Bill to continue to live with them in what they believe is "the best residential service you'll ever find." They describe their care for Bill as a *choice*. "This is all choice. We know this and this is OK." Kate and Clark understand that "as long as possible" does not mean forever, and they have made appropriate legal and financial plans to provide for Bill, including guardianship provided by a cousin and an appropriate trust as recommended by their attorney, a specialist in elder and MR requirements. However, the plan hinges on their continued good health. Any resources required for their own long-term care would necessarily be withdrawn from resources intended for Bill's future.

**The Franklin Family**  
**Urban setting.**

**At home:**  
**Esther, age 69**  
**Son Sam, age 44**

It is hard sometimes to tell day from night in the Franklin household. Sam's sleep pattern is disordered, and he rises for the "day" at 3 or 4 a.m. This may be explained in part by the recent upheaval in his life. Just six months earlier, Sam's older sister, with whom he had been living all his adult life, was shot to death in the kitchen of their home. Sam, who has intellectual disability and a psychiatric illness, was upstairs at the time. Because Sam has very limited language skills, it is difficult to know just how he has been affected emotionally. His mother Esther, who readily took him under her care in the midst of her own grieving, hears him crying at night. She is sure that he is bewildered and bereft. Esther, a retired widow, moved out of her senior housing complex where she was president of the resident council and had a wide network of social support, to a two-bedroom apartment that would accommodate her son. The arrangement is working well, given the circumstances. Sam's only other sister has a son of her own with a disability and her capacity to help is limited.

Sam is a bright-eyed African-American man of short stature who is often mistaken for an adolescent, so youthful is his appearance. Though fairly self-sufficient for his basic personal needs, Sam's medications, for seizures and for anxiety, must be monitored and dispensed. In addition to his intellectual disability, Sam has a psychiatric diagnosis that makes him a consumer of two systems of service: MR/DD and mental health. Sam receives Social Security and Medicare. He does not cook but is able to do laundry and perform other chores. In that regard, he is helpful to his mother, who has turned down an offer of PASSPORT homemaking services. In addition to caring for Sam, Esther must take special care of herself. She has had epilepsy since childhood and has coronary artery disease.

Sam has dressed himself and groomed himself before the van arrives at 6:10 a.m. to take him to his workshop. Work begins at 7:30 a.m. Sam's job consists mainly of packing boxes; he likes the work and the people he works with. According to his mother, "he doesn't like to miss a day." Sam can't read or write but was passed in the public school system from elementary to junior high. Ultimately, upon his mother's insistence, the school conducted an evaluation and determined that Sam had the "IQ of a 5-year-old." At age 18, he graduated from special education in the public schools. The workshop followed. Because Sam's psychiatric illness has manifested in a history of behavior ("temper") problems, Sam spent a short part of his childhood in institutional care. Esther describes this as "not up to par." "They were stealing his clothes, he was not getting haircuts, it wasn't working out, and he didn't like it either." In his current arrangement, and with his current skills, Sam cannot be allowed to leave the apartment alone because he does not have the judgement to handle transportation or the taunts and pressures from the neighborhood.

Sam arrives home at 4:15, and is understandably tired. His mother draws a bath for him, and he bathes himself. Esther fixes supper, which they eat together after Sam's bath. After supper Sam spends time in his room, listening to his beloved blues and jazz music on the radio. It is a very quiet life. He may come out to get a snack, but eventually "drops off" to sleep and will rise once again at 3 or 4 a.m. At that time, Esther will rise and have some tea, making sure

that Sam does not leave the apartment. For Esther, who is battling depression since her daughter's murder, this disturbance of her sleep aggravates her own need for rest. Today, Sam and Esther did not get to the nursing home for a visit with Esther's mother who has dementia. They try to visit 3 to 4 times each week. On Sundays, a church deacon takes Sam and Esther to church. Esther has ten very close friends who stand by and support her. For Esther, hers is an "unanticipated life."(Kraus and Seltzer, 1999) The arrangement that had Sam under the care of his sister for more than twenty years had worked well for all involved. An adjustment to this new arrangement is being made, steadily, and with a quiet dignity.

**Value of Informal Care: \$34,585 per year** (three roommates, extra staff for work closings).

**The Future:** Esther discusses the future with a composure that appears to be tinged with her lingering grief. She expects that Sam will live with her for "the foreseeable future," but imagines only vaguely what that future will hold. She is just beginning to carve out a life for herself and her son. Attorneys at her church have offered to help her with plans for Sam's future, but these have not been made. Sam's dual diagnosis yields the advantages and disadvantages of involvement with two systems of care; this will require continued coordination. For now, Sam's Support Administrator at the county board of MR/DD is the primary professional involved. Sam's remaining sister, whose own child has a developmental disability, has indicated that she is willing to be involved in Sam's care when her mother is no longer able.

**The Dewitt Family**  
**Urban setting.**

**At home:**  
**Nora and Arthur, ages 74 and 81**  
**Daughter Dorothy, age 52**

Dorothy Dewitt's day begins at 7 a.m. when she rolls herself out of her bed and onto the floor. From there, she scoots herself to the bathroom across the hall, by walking on her bottom and using her hands to propel her. She hoists herself onto the toilet where her all of her morning care takes place. From the bathroom, she shouts a loud, though slurred, hello to her visitor. Her mother and father, and Dorothy herself, are one finely tuned "care machine." Arthur has prepared breakfast and packed Dorothy's lunch while Nora irons Dorothy's clothes. Arthur fetches Dorothy's wheelchair and places it, just so, outside the bathroom door. With Dorothy still on the toilet, Nora helps her bathe and Dorothy brushes her teeth. Nora brushes Dorothy's hair, and applies her deodorant. She puts on her socks and sets fresh underpants and her freshly ironed slacks around her ankles. Arthur and Nora each tuck an arm under Dorothy's armpits and with a "One, two, three," she is lifted from the toilet, and in another coordinated maneuver, her underpants and slacks are slid up to her waist. Then Dorothy is assisted to her waiting wheelchair. (Dorothy is 5'5-1/2" and 180 pounds.). She requests her black shoes, which her mother fetches, slips on, and buckles. The rest seems almost easy. Though Dorothy's fine-motor skills are limited, she is able to wheel herself to the kitchen table, where, with some effort, she feeds herself a breakfast of coffee, orange juice, and a Metamucil biscuit. When the new driver of the van arrives five minutes early to take Dorothy to her workshop, the "care machine"

is thrown off its pace a bit. All adapt, however, and Dorothy is off for an hour's drive to the workshop.

Dorothy's primary diagnoses are mental retardation and epilepsy. She is on heavy doses of seizure medication, and this affects her ability to walk. She has limited communication skills, but knows and uses the names of every person in her beloved family. She has enough language to occasionally ask, "Why me, Mama?" She also has enough language to say she would like to have her own house. Nora says this "breaks her heart." Dorothy has only a couple of years of school, in the Catholic school system. She receives SSDI, and now, a small paycheck from the workshop. Dorothy is new to the MR/DD Board; she has been going to the workshop for two months. In her working life, Nora was a nurse at a multi-service community center, so she was not ignorant about public support. The Dewitts simply did not want the stigma or interference of help. Nora says, "It's very demeaning. It lowers my dignity." Dorothy's is a large and extended African-American family that has supported and cared for her all of her life. This morning, Dorothy's niece, Teresa, stops by to drop off her 8-year old son Ronald on her way to work. The regular baby-sitter had to cancel and Nora and Arthur are glad to substitute. Teresa is especially close to Dorothy, and frequently helpful to Dorothy, Arthur and Nora. Dorothy's Aunt Lucille stops in three times during the day, for a visit, and with an offer to grocery shop. One of Dorothy's brothers lives about ten minutes away, and he and his wife occasionally take Dorothy overnight. Two other siblings live several states away but are considerable emotional support. Nora talks to her daughter in Connecticut nearly daily.

Nora and Arthur are taking turns having knee replacements, so they have needed more help than usual in the past few months. It was one of their doctors who encouraged them to seek services. Now that they have a Support Administrator, they have relented to enroll Dorothy in Medicaid to qualify her for waivers and other benefits, such as a lift to help her transfer from bed to toilet to wheelchair.

Dorothy loves the workshop, and is having a hard time understanding why she can't report on Saturdays and Sundays. Today, she is packing boxes with sportswear. It is very slow going, but she is firmly planted at her workstation and the empty boxes don't seem to rattle her.

At 3:45 Dorothy returns from the workshop; it is a beautiful day, and the family sits on the front porch, Dorothy still in her wheelchair. Dorothy is a part of the neighborhood, and she enjoys watching folks pass by. At about 5 p.m., her mother senses that she is restless. She asks if Dorothy wants something, and Dorothy responds, "Dinner!" With that, Nora is up preparing fried chicken, baked beans, and tossed salad. In the middle of preparations, Teresa picks up Ronald, and Aunt Lucille drops by for one last time. The mail carrier pokes his head in to ask how everyone is doing. Dinner takes place after grace at 6 pm. in the sunny kitchen. This kitchen is the heart of the household, and apparently, the heart of this extended family. The family meets every Sunday over a large dinner at the same table.

After dinner, the family watches their favorite TV series, Nora folds laundry, and the "care machine" switches into gear for the bedtime routine, a reverse of the morning motion. In a few weeks, Nora will have her knee replacement, and family will gather 'round to provide care in every needed place.

**Value of Informal Care: \$34,585 per year**, based upon a group living arrangement with three roommates.

**The Future:** The DeWitts have the advantage of a large extended family who live nearby. With a well-coordinated combination of formal and family care Dorothy might well be able to remain in her own home, even with her many care needs. For now, Dorothy's Support Administrator has been talking with the family about the possibility of a group home, and Dorothy's parents appear to be comfortable with that prospect. Dorothy is not so sure; she is likely to appeal for the chance to live alone. Difficult decisions will be negotiated. A significant decision, to accept services from the county board, has already been made. Dorothy's enthusiasm about the workshop is an encouragement to the family and should smooth the way for other changes.

**The Yordy Family  
Suburban setting.**

**At home:  
Della and Dwayne, ages 66 and 73  
Son, Stanley, age 43**

Stanley is wakened by his parents at 7:15 a.m. His father Dwayne lays his clothes out and Stanley gets himself dressed. Stanley is tall (6'1") and handsome ("adorable," in Della's terms). He can perform almost any skill asked of him, but does not appear to have the judgement or initiative to take care of himself from one task to the next. Stanley, an earnest student of the road atlas, can tell a traveler how to get from one Ohio city to the next, but could not go through the steps to get there himself. In Dwayne's words, "Stanley has a lot of information, but he doesn't know what to do with it." He can read "everything he picks up," and has an extraordinary memory for detail, yet cannot hold a conversation without significant perseveration and obsessiveness. Stanley had German measles at age 18 mos. and "suffered a brain fever." Since that time, he has never been left alone, except for a frightening twenty minutes when Della and Dwayne were stuck at a railway crossing just as Stanley's van dropped him off at home. Stanley was fine, and the Yordys are now teaching Stanley to lock the door behind him when he lets himself in the house, even if they are sitting in the living room.

Stanley leaves for the workshop at 8 a.m. Today Stanley assembles U-bolts at the workshop. He seems rather indifferent to the work, but gets the job done. Stanley is supported by a combination of SSI and Social Security. He spent his youth in special education classes. He takes a psychotropic medication three times a day to calm his agitation, and other than some digestive problems he is healthy.

Della and Dwayne, on the other hand, are not so healthy. Della has had several heart attacks, including open-heart surgery. She's had a hip fracture. She also has asthma and bronchitis and uses oxygen daily, sometimes for 24 hours. Dwayne has had cancer. They receive PASSPORT homemaking services five days a week. Stanley is a help to his parents. He dries dishes, runs the vacuum, and carries out trash. He does all the heavy lifting and the finer deeds like taking his mother's shoes off while she lies in her recliner. The other children, Della's and Dwayne's by first marriages, are not a source of help to the Yordys. One of Della's grown, married sons is unusually dependent on her and a constant source of stress and concern. A beloved son died in a car accident several years ago.

At 3:10 Stanley arrives home from workshop and lets himself in. He forgets to lock the door behind him, and Della wonders aloud if he will ever learn to do that. He empties his lunch

pail and heads to his bedroom, comes out again, and goes back in again, talking to himself. Dwayne says, “Did you wash your hands?” and Stanley responds, “Wash your hands, skwatchee.” It is clear to his mother that he wants the newspaper; she hands it over, and he heads to his bedroom to read. This occupies him until it is time to go out to dinner. It’s their regular night out, and Stanley chooses the restaurant. Della and Dwayne treat him lovingly and gingerly; if Stanley gets mad, he throws things and slaps his face. At the restaurant, Stanley eats his meal in less than five minutes. It is a short outing.

In the evening, Stanley watches his television programs in his bedroom, while Dwayne and Della watch theirs in the living room. This gives them all “space” in their household. At bedtime, Della tells Stanley, “See you after seven,” when she’ll wake him for another day.

**Value of Informal Care: \$71,000 per year**, based on current costs of IO waiver funding and Stanley’s need for medication supervision.

**The Future:** Della speaks about Stanley’s future with considerable anxiety but little notion of what arrangements are possible. She says, “I want whoever has him to take good care of him. I want people to love him. To love him. I don’t want him beaten. I don’t want him hurt.” No plans have been made for Stanley’s future and his parents’ fragile health renders his current situation fragile as well. There is no prospect of sibling involvement. Stanley’s future care is likely to be decided in a crisis, first in an emergency placement, and then through a waiver slot as it becomes available.

**The Norman Family**  
**Rural setting.**

**At home:**  
**Martha, age 72**  
**Daughter SaraJane, age 39**

Night and day might well be indistinguishable to SaraJane. Her family thinks she has no vision, but can’t be sure; SaraJane’s brain damage makes testing impossible. Thirty-five years ago, SaraJane was the only one of her family seriously injured when their car was hit and spun around, throwing all four Norman children out onto the highway. The trauma to SaraJane’s head caused a loss of brain matter in the frontal lobe area. Sara’s limbs move, but not voluntarily. She does not communicate in any meaningful way, and she is dependent on others for every bodily function with the exception of swallowing and urinating. She must be spoon-and-syringe fed; caregivers must manually stimulate her bowels through her rectum. SaraJane cannot roll over, and it is to the credit of all who have cared for her that she has not had a bedsore in 35 years. When she is moved with a Hoyer lift to her chair, SaraJane cannot support her head. Even with all this, those around her do what they can to add some quality to her life. Her mother Martha says, “Never once did we think of putting her in a nursing home. We felt that there was some recognition of us, and that’s all she had, so that’s what we gave her.” The family did not begin to get formal, public services until SaraJane was nearly 22 years old, and those services were limited.

This morning, as usual, SaraJane squirmed at about 4:30. Martha, who sleeps in a bed in the same room, got up to give her a syringe full of water, which satisfies SaraJane until about 5 a.m. By this time, one of SaraJane's three home care workers has arrived. The home care workers are doing extra duty these days because Martha is recovering from major abdominal surgery and cannot do any lifting. During her recovery, Martha is getting help with SaraJane 12 hours a day, five days a week. During this health crisis, her daughter Nan and daughter-in-law Laurel have helped on the weekends. Ordinarily it would be Martha who turns SaraJane at 5 a.m., but Cheryl is working a 12-hour (5 a.m.-5 p.m.) shift today. In a couple of weeks, when Martha can lift again, Cheryl will go back to an 8-4 shift, four days a week. Another caregiver will take the fifth day, and the third caregiver, who has been with the Normans for twelve years, will go back to taking Wednesday evenings and Saturdays. Nan and Laurel will cease their weekend duty.

Cheryl spends her whole shift simply tending to SaraJane's most basic needs. At 8:15 a.m., after a turning and diaper change, Cheryl feeds SaraJane her breakfast. It is a pureed mixture of oat bran, scrambled eggs, strawberry Ensure, and medications. Feeding SaraJane takes 45 minutes and Cheryl sits throughout the process. At 9 o'clock Cheryl washes SaraJane's face and brushes her teeth. She does some range of motion exercises with SaraJane's limbs. By 9:40, it is time for SaraJane's bath. SaraJane's bath is a choreographed series of lifts and turns and the manipulation of bed, washbowl, shampoo, cloths, towels and lotions. At mid-morning, Cheryl's attempts to stimulate SaraJane's bowels are unsuccessful and Cheryl will try later. It is time to use the mechanical lift to transfer SaraJane to her chair, a soft recliner next to her bed. SaraJane will sit there for no more than two hours, the limit of her tolerance for it. Cheryl reads to SaraJane; Cheryl believes that SaraJane listens to these stories and understands them; SaraJane's mother is not so sure, but does believe SaraJane responds to tone of voice. When Cheryl is not providing hands-on care to SaraJane, she spends time doing housecleaning and laundry chores. She is never idle. The morning sequence of caregiving tasks, minus the bath and bowel stimulation, gets repeated mid-day and early evening.

Now that she is feeling better after the surgery, but still following her "no-lifting" order, Martha is able to actually savor the extra help. It creates some freedom she hadn't otherwise enjoyed, and she will miss it. Martha's husband left the family when SaraJane was 22 and Martha has had to cobble together both living and home. When her husband left the family, he also precipitated the collapse of the family's mission and livelihood: they had built and run a Christian school that thrived on a shoestring budget. Martha relied on the community of this school for financial and instrumental support. When that evaporated, she went back to school to earn a masters degree, and, for a time, ran a small school out of her own home. These days, Martha depends on what she can make from giving piano lessons, a very small Social Security check and her daughter's SSI and Social Security.

When the Wednesday evening caregiver arrives early, at 4:20 p.m., Cheryl sits to visit with her for a while before leaving. Martha prepares to go to church; because she doesn't have help on the weekends, her church going is restricted to Wednesday nights.

**Value of Informal Care:** SaraJane is receiving care through the Individual Options Medicaid Waiver, which was maintained on an appeal from the family. This waiver is actually available to people who would qualify for an ICF-MR level of care, and benefit from "active treatment." The appeal to keep SaraJane at home through the IO waiver was granted because she had been receiving home care services for nearly two decades. SaraJane's IO waiver allotment is the

second highest in the county (\$40,398 per year); she receives 40 hours per week, plus some reserve hours for special circumstances, such as Martha's recovery from surgery. Should SaraJane's family be unable to keep her at home, SaraJane would require nursing home care at the Medicaid State average reimbursement rate of \$131.79 per day<sup>32</sup>, or \$48,103 per year. The value of informal care provided by SaraJane's mother is that amount minus the formal support she is now receiving for a total of **\$7,705 per year**.

**The Future:** Martha's faith is important to her and she credits it for surviving the past and facing the future. She says, "I have laid hold on the promises of God that He will let me live long enough to care for SaraJane the rest of her life. I firmly believe that the Lord will allow me to live as long as SaraJane lives." While Martha expresses her deep appreciation for the support she has received from public services and benefits, she says, "I have much more faith in the Lord than the U.S. government. We are going to handle [the future] in faith." Martha regards herself as a person who has coped with enormous adversity already, and she believes that she can handle whatever is to come. Martha has resisted making plans, including a guardianship, for SaraJane. However, even with her belief that she will be allowed to care for SaraJane through her lifetime, Martha is willing to at least talk about an alternate scenario. She believes that, should she die or become too impaired to provide care, her daughter Nan would take SaraJane in. No formal agreement has been made, however, and Martha has not extracted a promise from her Nan. She "told her that if she absolutely has to put SaraJane in a facility, I do not want her to feel guilty." Martha says, "I won't deny that here weren't times that I looked down the long desert trail in front of me. But it is unfruitful to think about it, because it might never happen."

**The Strauss Family  
Small town setting.**

**At home:  
Phyllis, age 75  
Son, George, age 43**

At 6:30 a.m. George and his widowed mother Phyllis are eating a quiet breakfast at their kitchen table. The sky is still dark outside, but George's bus comes at about 7:30 and he wants to be ready. George is a tall, clean-cut, neatly dressed man who is very capable of most self-care skills. Although his intellectual disability limits his ability to work in the community, he did have a few successful years as a custodian in supervised employment at a department store until it closed. Now he works as a custodian at the area workshop, and is valued there as well. George is unable to read or write, and has limited arithmetic skills. His speech is somewhat impaired by a stutter; even so, he is talkative and inquisitive. After breakfast, George shares his championship basketball medals and photo with pride; Phyllis beams.

When George was born, it was immediately evident that there were problems; doctors told his parents that he would never walk or talk and that they should "put him in an institution." This was never considered. Says Phyllis, "I just couldn't!" Instead, George's parents, like most of their generation in similar situations, made the best of things at home. Without services, they

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<sup>32</sup> Office of Ohio Health Plans, (2001) Ohio Department of Job and Family Services, "Long-Term Care Reimbursement", Fact Sheet 1.3.

improvised. Hard work and creativity went into teaching every skill: talking, eating, dressing, toilet training, shoe tying. Shirt buttoning, and particularly walking. George's parents made leg braces out of rolled up *Life* magazines and tied him to a wheel-fitted, crooked-leg table that became his support and momentum as he worked his way around the house. Thus, the boy who would "never walk" grew to be a basketball player. And the boy who would "never talk" now talks so much he "sometimes gets on [the] nerves" of the very mother who taught him how.

Ultimately, George's parents got support from the county MR/DD school, and Phyllis sings its praises long after George's graduation at age 21. The school taught George many fine-motor and daily-living skills. George uses these skills not only to care for himself but also to care for his house and his mother when she needs it. As Phyllis recovered from hip replacements, George was her right-hand man and nursemaid. He shovels snow, washes windows, and cleans house. He helps with dishes, but does not cook. He does not mow the lawn, a task performed by Phyllis's son-in-law. Phyllis says, "I could not stay in this house without George's help."

Also helpful are Phyllis's two daughters who live in and near town. Today, one of them comes over for lunch, a regular Tuesday "date." Both daughters have children and are professional women with "their own lives;" one daughter does daily battle with a chronic illness. In spite of demands elsewhere, both daughters are legal guardians to George and are actively involved in decisions about his life. George has made many friends through school, work, and his neighborhood. He has also lost many friends; his mother estimates he has mourned the death of nearly fifteen people once close to him. After his father's death, at George's age 17, George began to suffer extreme anxiety, a problem for which he takes daily medications. His very high blood pressure is also managed with medications.

George demands a strict routine in his day, and any disruption to his routine agitates him. George insists that his mother recite The Lord's Prayer with him at precisely 7:30 each evening. He takes meticulous care of his room and his clothes; he neatly prepares and packs his own lunch. He walks his dog morning, afternoon, and evening. Nearly every day, he visits a frail older woman in his neighborhood, bringing in her mail and chatting a while. After supper he takes a few trips around the block on his three-wheeled bike.

George is trying hard to learn to organize and take his own medications. Because George takes strong psychotropic and blood pressure medications, the potential for mistakes worries his mother considerably. This is one of the concerns that have Phyllis reluctant to pursue a supported living arrangement for George; she frets that there would not be adequate supervision. Concerned about the future, Phyllis would like to move by herself into a smaller space, perhaps an apartment, but she lacks confidence in the safety of proposed arrangements for George. She also must deal with the emotional effects of a separation. When she raised the prospect to George, he said, "Mother, don't you want me?" It has been hard to bring it up again.

**Value of Informal Care: \$45,000 - \$50,000 per year**, based on the scenario outlined below.

**The Future:** George's sisters indicate that they would like for George to remain in the family home upon his mother's death. The house would be owned by the daughters and shared by another adult, with 24-hour provider care. Concrete plans have not been made.

**The Cady Family**  
**Rural setting.**

**At home:**

**Miriam, age 70 and Liz, age 52**  
**Miriam's Daughter: Melissa, age 31**  
**Miriam's Son: Jim, age 35**

The stately Cady farmhouse is home to a family within a family. It is a place of imagination and courage, having become such a place in the face of many obstacles and hurts. Today, by 8 a.m., Miriam's children, Melissa and Jim, are dressed and ready for their ride to the workshop. Also ready are seven other adults with a wide range of disabilities who live in the Cady farmhouse. Now a licensed group home, the household represents three decades of innovation and adaptation. Through it all, Miriam, a healthy and vibrant 75-year-old, has managed to maintain her role as mother to Jim and Melissa, as well as to her eight other children (five adopted and three biological) even as she became a licensed provider to others.

Jim was born after Miriam and her husband had already adopted five healthy children. Jim's cerebral palsy and mental retardation were diagnosed at ten weeks. Melissa was born four years later, with two healthy children born in between. Soon after Melissa's birth, Miriam identified the same signs of developmental delay that Jim had shown as an infant; Miriam's diagnosis was confirmed, on her anxious insistence, in the first few weeks of Melissa's life. Neither Jim nor Melissa walks. They get around the house by creeping on all fours and use wheelchairs in public places. Jim needs help transferring from bed to chair, to wheelchair, to toilet, while Melissa is able to do her own transferring where there are grab bars or other supports. Melissa is verbal, but Jim is not. It is clear, though, that Jim has a good understanding of language and he communicates through a combination of a communication board, his own sign language, and a vocalization of "yes" and "no." In spite of a speech impediment, Melissa is easily understood by those who communicate most often with her. Though neither reads or writes, Jim is able to discriminate among record labels in his record collection, a skill Miriam wishes she could "tap into" somehow. Jim is frustrated by his limitations and is sometimes aggressive.

When Jim was born, Miriam "knew nothing about mental retardation," and doctors offered little but the suggestion that he be institutionalized. Instead, Miriam began what would become a lifelong crusade to provide services for her child and others like him. Because Jim was not ambulatory or toilet-trained, he was ineligible for the only program available in their rural county. Miriam searched and found families whose children were also excluded from the system. In 1971, as a cooperative venture, a handful of families established a training center based on the controversial Doman-Delacatto method (out of Philadelphia's Institutes for the Achievement of Human Potential). The families were able to persuade both state and county to designate funding for the center. Melissa enrolled at age 1. This was also the time of deinstitutionalization, and when the Cadys brought a five-year-old boy out of Orient State Hospital to live with them, it was to be the first of many in this family-within-a-family. The mother who "knew nothing about mental retardation" is now the owner and operator of two licensed group homes, and a direct care provider in the Cady farmhouse.

Miriam and her husband were divorced 22 years ago, and Liz, who was a teacher at the training center, became a part of the family. Although this caused somewhat of an uproar in this

conservative rural community, it is noteworthy that Miriam and Liz now care for the daughter of one of their earlier adversaries. While Miriam owns the properties, Liz is the president of the board, and Miriam vice president. Miriam's youngest daughter, Rachel, and Rachel's husband Dale work full time as house manager and direct care worker respectively. Liz and Miriam also work as direct care providers. So, at the same time that Miriam and Liz care for Miriam's own children, all others are cared for like family. Each day begins at 6 a.m., and at 5 p.m. Miriam and Liz retreat to a small house in back of the farmhouse for a four-hour break. Just recently, they have been able to enjoy weekends off on a fairly regular basis.

Miriam, who takes a salary only after all staff and bills are paid, made no money last year. Liz made very little. Yet both express deep satisfaction with life in this household. Very recently, Miriam relented to designating an empty slot in the home to Melissa's care; thus Melissa's care is now publicly financed, while Jim's care continues to be provided out of his mother's own heart and pocket. This arrangement highlights the value of the care that Miriam has been providing to her own children all along--- approximately \$100 a day for each. When Melissa reached the top of the county waiting list, Miriam had every right and every good reason to place Melissa in the ledger book, yet she struggles with the decision even so. Miriam's concern with the blurring of Melissa's status and the loss of her slot to "someone else who might need it" reflects the ambiguity of expectations about the responsibility of families and government in these situations. For many years, Miriam accepted public support for the care of children of other parents who were then free to live their lives unencumbered by Caregiving. It is remarkable that she has anguished about taking that support to care for her own child.

**Value of Informal Care: \$38,000 per year (group home) to \$102,200 per year (ICF-MR).**

### **The Future:**

Miriam has made careful legal arrangements to maintain the property as a group home until the deaths of Jim and Melissa should Miriam predecease them. She has worked with a legal expert to assure Jim's and Melissa's future security without jeopardizing their eligibility for services. Jim and Melissa have a sister and brother-in-law, Rachel and Luke, who are committed to them and to the group home, which they intend to maintain. It is possible that Jim could assume a slot in the group home in the same way that Melissa did. This would represent a technical "transition" from family to formal care; in actuality, Rachel and Luke would be right there, carrying out the family care Jim and Melissa have enjoyed all their lives.

### **The Mandel Family Suburban setting.**

#### **At home:**

**Mary, age 68, and Ed, age 69**

**Daughter: Olivia, age 27**

She loves to take bubble baths, play with her Barbie dolls, go dancing and golfing, watch live theater and movies, eat out and travel, and she gets to do all of these. Olivia, a 27-year old with Down Syndrome, lives with and is cared for by her 68-year old semi-retired mother and her 69-year old fully retired father. Olivia works in minimally paid employment at a sheltered

workshop three days a week from 9:00 a.m.-3:00 p.m., and volunteers at an agency center (Abilities First) twice a week from 8:30-11:30 a.m. Her parents provide all transportation.

Described by Mary as “moderately functioning,” Olivia needs nevertheless around-the-clock care and supervision because of insulin-dependent juvenile-onset diabetes which started when she was 13 years old and which necessitates blood sugar measurements and insulin injections four times a day, from the time she rises at 8:00 a.m., to the time she goes to bed around 11:00 p.m. Both parents can and do measure her blood sugar and give her insulin injections. The diabetes also requires that the parents monitor all food and liquid intake, and plan snacks throughout the day. In addition to the management of diabetes, the parents administer vitamins and one daily dose each of 0.125 mg Synthroid (for a thyroid dysfunction) and 20 mg Aciphex (for stomach acid reflux). Dermatitis requires occasional use of medicated shampoo. Although Olivia can and does wash her own hair, her mother does it for her whenever she feels she needs to apply medicated shampoo. Her mother also helps occasionally with brushing teeth to make sure this task is done properly, cuts Olivia’s fingernails, and takes her to a chiropodist for toenail care because Olivia “is a bit touchy about her feet.” Although Olivia can perform all activities of daily-living (ADLs), she needs cueing, reminding, coaching, and monitoring for the timely performance of most of these activities. The parents do this in a patient, caring, calm, indulgent and effective manner.

Mary and Ed also engage in a host of social activities either specially planned for Olivia, or explicitly intended to include her. These include weekly softball games and weekly dance lessons with other MR/DD children organized and paid for by parents who constitute a very active support group and who all eat out together after the dancing classes; playing golf with her father and brother-in-law every Sunday; attending plays at theaters in Cincinnati and the surrounding towns on a regular basis; going to movies and eating out regularly; and taking several trips a year with other MR/DD children and their parents. Another amenity Olivia’s parents provide are three 44-mile round trips a week to take her to the workshop which they say “is nicer and smaller and more family-like” than the one nearer to them and to which agency transportation would be available.

Olivia has three older siblings (ranging in age from 45 to 49). Two sisters and one brother live within a radius of 3-10 miles from her parents’ house and provide intermittent care as needed, but Olivia’s mother calls on them sparingly so as not to burden them. One of the sisters is in charge of the trust the parents have established for Olivia.

The formal services currently used by the family are Olivia’s employment in the MR/DD Workshop, and a Therapeutic Recreation/Leisure Coaching service that provides recreational outings at the users’ requests. According to Olivia’s mother, there is no limit on the frequency of this service. Actually, the family does not use this service much because they already participate in many activities organized by the parent group. In any case, Olivia’s mother would have to come along on outings with the Therapeutic Recreation/Leisure Coaching to manage Olivia’s diabetes, and therefore they all prefer to engage in activities with the congenial parent group they have befriended.

**Value of Informal Care: \$40-60,000**, for staff time only; **excludes** housing, transportation, living expenses (food, etc.), and contract home health nursing for diabetes management.

### **The Future:**

Olivia receives Social Security as a dependent of her retired father and earns minimal income from her employment in the workshop. These two sources of income alone could not support the lifestyle that her parents so generously and lovingly bestow on her. They have established a trust fund in her name to ensure her continued support after their death. Olivia's current lifestyle would be jeopardized if her parents became physically unable to care for her. Having to buy help for themselves and for Olivia would put considerable strain on their financial resources. It seems that the adequacy of the trust is predicated on the parents' continued ability to care for Olivia up until their death.

Both parents and their other children refuse to even discuss the possibility of placing Olivia in a group home. The siblings have indicated that they would take care of Olivia, but her mother hesitates to count on this. She and her husband set up the Trust Fund, which would be sufficient to pay the \$2,000 a month for a home in Franklin, Kentucky, that her husband visited and liked very much. But their resources would not be sufficient to pay for that home for any extended period while they are still alive. Olivia's mother admits that they haven't really made a decision, haven't really talked about "it" in any conclusive way, and that she worries more about Olivia's future than does her husband. It was only in the context of a discussion about planning for Olivia's future that her mother did mention the burden of managing insulin-dependent diabetes, implying that nobody else could be expected to carry out this task as willingly and reliably as they do.

### **The Letky Family Suburban setting.**

**At home:  
Douglas, age 75  
Daughter Betty, age 45  
Sister and brother-in-law in an apartment upstairs**

She loves to play the card game UNO and she loves to win. When she loses, she accuses her partner, usually her father, of cheating. She has a palpable sense of humor and loves to tease and be teased, and her father, sisters, nephews and nieces indulge her in all of these. She also loves to sit quietly and hold hands with her sister, claiming, with a twinkle in her eye, "Betty take care of Lorie." It's a joke and she knows it.

Betty is a 45-year old woman with intellectual disability who went to school, graduated at the level of first grade in reading and writing, was ambulatory and could perform all activities of daily-living in the sheltered environment of her parents' home. Photographs of Betty at different ages attest to a life lived fully within the limits of her condition. All this changed when she suffered a stroke in 1988 which left her paralyzed on her left side, unable to get up or stand up on her own, unable to walk, and unable to perform any activities of daily-living except eating bite-sized prepared pieces of food and drinking through a straw. She has some independent mobility: using her right hand and leg, she wheels herself from her bedroom to the kitchen and back. Surviving the stroke was considered short of a medical miracle, and her continued survival depends on a battery of medications. She has swelling in her legs which periodically gets so bad that she is left in bed for a day with a double dose of a diuretic. Her vocabulary is limited, her

speech is slurred and difficult to understand, and she is hard of hearing. Betty is continent but requires anywhere from seven to twelve trips to the toilet daily. The family rejects the idea of putting her in a diaper and is motivated to preserve her continence. To prevent accidents during card games, when Betty is most likely to ignore the need to go to the toilet, they remind her. She herself signals her need for help with toileting by wheeling herself from the kitchen to her bedroom. During the night, she calls her father, whose bedroom is right next to hers, and he brings her a bedpan. Usually this happens once or twice each night.

Betty's major caregivers are her 75-year old father Douglas, a Central European immigrant of German background, and two sisters, Mary age 39 and Lorie age 41. Lorie and her husband and daughter live upstairs in the same very small house as Betty and her father, and Mary lives five miles away. Lorie, who has a full-time job, moved in with her father to help with caring for Betty. Lorie used to get Betty up and dressed in the morning, and put her to bed in the evening. These are strenuous tasks because Betty weighs 280 lbs. When Lorie pulled a ligament in her knee, she could no longer do the lifting, and now Mary performs both the morning and the evening routines. Mary had also taken care of their mother during the last five years before her death of Parkinson's disease in 2001. The sisters and their father perform their caregiving tasks cheerfully and lovingly.

Although Betty is basically "dead weight," they have ritualized the job of getting her up and transferring from bed to toilet to chair in a way that gives Betty a role of active participation. These tasks are accompanied by a chorus of voices, including Betty's, that chant "one-two-THREE- UP" and are followed by compliments for Betty on a job well done. Her caregivers never ever leave her alone, even for short periods, although Betty often watches television for hours in the afternoon. Mary has a part-time job, and she and her husband work around each other so that one can always be with their kids and also provide help with Betty. The sisters are worried about their father who clearly would not be able to manage by himself. Short trips to the grocery store are the social events of his life. Planning these trips that last not much longer than an hour takes up a good part of his morning and helps him structure a daily schedule that otherwise lacks variation and stimulation. It is his way of managing a caregiving situation that is both demanding and tedious. Together, Betty's father and two sisters provide around-the-clock supervision as a matter of fact, without exception or compromise.

Neither Betty nor the family receives formal services. The family is reluctantly exploring a sheltered workshop. They question the staff's ability to meet Betty's needs, and they have concerns about safety and security. They described a trip in the community van to obtain an ID card for Betty that would allow her to use this transportation service on a regular basis. However, the ride in this van was so "scary" that the family has been reluctant to use this service again.

Betty has Medicare and Blue Cross/Blue Shield Group insurance through her father's pre-retirement employment. The latter reimburses 80% of her considerable medication costs. She is Medicaid eligible, but so far the family has not applied because of the means-testing requirement, and because they believe that as a Medicaid patient Betty would not be allowed to use the local hospital that is close enough for her father to visit.

**Value of Informal Care: Basic minimum \$50,600** (assuming that Lorie becomes certified and contracts as paid provider; workshop; transportation)

**\$76, 949** (in apartment with roommate, including workshop, housing/food)

**\$134,658** (in apartment without roommate, including workshop, housing/food)

### **The Future:**

Mary's dream is to be able to buy a big accessible house in which they could all live together, and in which taking care of Betty would be easier, more agreeable for everyone, and more efficient. It is unlikely that this dream will come true. Mary works part-time in a clerical position in a hospital, her husband is a fireman, and they have four children ranging in age from 6 to 13. Lorie works full time in a clerical job for a publisher, her husband is a mechanic for a trucking firm, and their daughter is hoping to go to college in two years. The current caregiving arrangement is fragile in the sense that if anything should happen to one of the three major caregivers, it would put undue strain on the others. For example, the precariously balanced interdependence between the main actors would be jeopardized if the father became disabled. He did have a heart attack shortly after Betty's stroke, and Mary took off from work to look after him. But that was before she had four children.

The family vehemently rejects the idea of a group or nursing home for Betty, although they visited one after Lorie hurt her knee. Instead of pursuing the nursing home option, they organized the current arrangement and seem satisfied with it. Mary is talking about buying a van, which would allow them to take Betty out to places like the zoo. Currently Betty does not get out of the house at all, partly because she is so difficult to move, and partly because the neighbors they knew when they were growing up have all gone. Mary says that the new neighbors do not know Betty, and that the neighborhood is no longer safe. She would not feel comfortable taking Betty out in the street. Their caregiving life is lived in a small house where visitors seldom come. According to Lorie, not being able to see and receive friends is the most difficult aspect of looking after Betty. They have no clearly articulated plans for what will happen once their father dies; all they know is that they will somehow manage to continue to take care of their sister, no matter the cost.

### **The Atkins Family Suburban setting.**

**At home:  
Alice, age 84  
Son Barry, age 58**

The first impression Barry, age 58, makes is that of a handsome man with good social skills: he knows how to greet a stranger with an engaging expression and asks appropriate opening questions. However, this first impression dissipates quickly when it becomes apparent that his social interactional repertoire and his cognitive skills are quite limited. Barry was deprived of oxygen at birth and has intellectual disability. He relies on his widowed mother Alice, age 84, for all instrumental activities of daily-living: she keeps house, does his laundry, shops for groceries, takes him shopping, provides supervision, monitors his social behaviors, makes sure he gets up and ready for work, drives him places, helps him cross the street (He was once hit by a car), negotiates with outsiders on his behalf, and basically tells him what to do next. Barry can and does perform all personal care skills. In addition, he diligently mows the grass, sets and clears the table, makes his bed most days, decides what to wear, and lays out his clothes the night before. All of these require cueing and supervision. It is clear that, while he relies on his mother for many instrumental tasks, he also has many capabilities.

Barry's ability to read and write at the 1<sup>st</sup>/2<sup>nd</sup> grade level is the result of Alice's untiring efforts at a time when public schools had no special education programs. After a brief and disappointing experience with public school, his parents sent him to private school through the sixth grade, and after that, his mother home-schooled him. He has many talents and is clearly very smart. Alice thinks that he had the makings of a genius: he demonstrates an uncanny hand-eye coordination when he puts together 700-piece jigsaw puzzles, and he is now learning how to use a computer under the tutelage of a person hired by his mother. His parents' unwavering belief in his abilities and their unrelenting determination to help him realize his abilities is the thread that runs through the story as told by his mother. At every turn of the story, the listener is impressed by the fact that, but for a tiny delivery glitch, Barry would have had a very different life. Thanks to his mother, he has as full a life as the glitch will allow: he lives in a spacious, comfortably furnished house in which he has his own bedroom, another room for his projects, the family room for his puzzles, and most recently the living room for his computer. He cares about his appearance, and his mother takes him to buy fashionable clothes. When he decided recently that he wanted to lose weight, he asked Alice to put him on a SlimFast diet, and she obliged. However, this has not dampened his enthusiasm for family outings to restaurants.

Barry is embedded in a relatively small but caring network of kin of which his mother is the center. Two younger siblings are as supportive as they are able to be. Barry's sister lives several states away, and his brother Hank, who is married with children and has a masters degree in special education, lives 30 miles away. Hank helps out by involving Barry in his own family activities.

Barry attends a workshop through the county board, from 7 a.m to 2 p.m. each weekday; there he assembles small parts. Barry is a beneficiary of Medicare and recently his eligibility for Medicaid was established, although the family has not activated it.

### **Value of informal care:**

(This county provided written estimates based on three scenarios, each with its own set of assumptions. The summary of estimates is unedited, with the exception of deleting the county name)

#### **(a) Living at home with some natural support.**

Assumptions:

-Due to Barry's functioning level and his familiarity of his home and surroundings, no third shift supports are needed.

-Sister living several states away can assist with advocacy issues and review the types of services being provided to her brother from time to time. Occasional phone calls and visits when in the [county] area. The impact to overall cost of care-\$ 0.00.

-Brother living 30 minutes away can assist with the designing of services needed for Barry, monitor services, and attend any team meeting to help revise/update his serve plan to best meet Barry's needs and assure ongoing attempts are being made to continue his brothers placement at home. Again due to the fact that his brother lives so close, provide assistance to recreation and social activities in the community, as well as a weekly invite to dinner with his family. The impact to the overall cost of care-\$13,299 (15 hours of family supports X 17.05 provider hourly rate X 52 weeks a year).

**Chapter 19 Total annual cost of services=\$54,969.00**

**Chapter 20**

**Chapter 21 (b) Living at home with no natural supports.**

Assumptions:

-Due to Barry's functioning level and his familiarity of his home and surroundings, no third shift supports are needed.

**Chapter 22 Total annual cost of services=\$68,268.20**

**(c) Living outside home in a residential setting.**

Assumptions:

-Due to level of services needed, Barry is eligible for services provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR).

-Most appropriate ICF/MR placement in his county would be that of a "community" ICF/MR. The make-up of this type of facilities is 8-10 individuals living together in a 24-hour setting.

**Total annual cost of services=\$80,300.00.**

**The future:**

Barry is his own guardian. Alice is unsure about how long this will last and what to do. She has been reluctant to declare him incompetent because she does not want to deprive him of his legal autonomy. No plans have been made for the future. Alice would like to count on Barry's brother Hank, but without "burdening" him. The future role of the siblings is unclear.

**The Kenagy Family  
Small town setting.**

**At home:  
Violet, age 86  
Daughter Eleanor, age 46**

Eleanor is a 46-year old with Down Syndrome who loves to crochet and has a pile of 20 or so coverlets to prove it. According to her mother Violet, this is the only activity she likes to engage in, and when it comes to exercise, she has no interest. Reluctance to move is one reason Eleanor, who is only 4 feet 10 inches tall, weighs over 200 pounds. Because of her weight, she cannot reach her bottom, and therefore her mother has to clean her after toileting. Violet also bathes her with a hand-held shower ("to be sure it's done right"), washes her hair because of Eleanor's long history of ear infections, cuts her hair, cleans her ears, and grooms her nails. Violet keeps house, shops for groceries, prepares food, does laundry, and provides supervision to assure Eleanor's safety around the house. Eleanor is ambulatory; she dresses herself, brushes her teeth, chooses and lays out her clothes for the next day, and tidies her room. She sets the table and washes dishes every night. She gets her own breakfast and can open a can and make a sandwich so that "she would not starve if she were alone for a while." Her mother can and sometimes does leave her alone at home for an hour or two. Eleanor's mental/cognitive abilities

are quite low; she cannot deal with concepts. She talks a lot to herself or imaginary people – mostly her Downs boyfriend David. In spite of her low level of cognitive functioning, her mother considers her “low maintenance.” Eleanor is quite content to spend a lot of time alone, listening to country music, or crocheting.

Eleanor gets out four days a week by attending a sheltered workshop Monday through Thursday; she leaves the house at 7:30 a.m. and returns at 3:30 p.m. Aside from Eleanor’s work, both Violet and Eleanor are basically “home bodies,” which is a good thing, because driving at night is a problem for Violet, and there is nobody else to provide transportation to some of the events Eleanor might attend. Eleanor does not even like to go out to eat, although sometimes she’ll send her mother out for carryout food. They clearly enjoy each other, and Violet is certain that she would “mold and mildew” without Eleanor’s company. While the mother performs many tasks for her daughter, she also gets a sense of fulfillment from her role. It took her many years to accept her daughter’s condition, but with age, she has managed to embrace her lot with a sense of peace, calm, and satisfaction.

**Value of Informal Care: Annual minimum: \$40,550** (annual cap \$25,550, supported living, plus \$15,000 allowance for a program of choice, e.g. workshop, day program, etc.; excludes transportation costs) **Annual maximum: \$102,200** (ICF-MR)

**The Future:** Violet refuses to worry about the future, although she thinks about it; what shape Eleanor’s life might take is not clearly defined in her mind. Obviously, no plans have been made.

The group home waiting list in this county is as long as the number of consumers now living in them. There are five “urgent” cases on the waiting list.

## **Chapter 23 DISCUSSION**

What have we learned from these twelve families? They represent a broad range of circumstances and experiences, but also have much in common. As a group, they illustrate the complexity of Triple Jeopardy; as distinct families, they remind us of the futility of broad assumptions and the importance of individualized approaches to planning and decision making. In this discussion, we pay particular attention to life stage issues and dynamics, the “sibling question,” and issues for facilitating planning in Double Jeopardy families. Finally, we discuss the value of informal care in Ohio and make recommendations for future study.

### **Chapter 24 Life Stage Issues and Dynamics**

The concept of perpetual parenthood sensitizes us to the reality of parental responsibility and involvement through the adult years of a son or daughter with a developmental disability. This level of involvement contradicts our expectations about parent and child roles across the life course; it requires radical adaptation in a society structured around child “launching” at age 18 or so. There are no rules or guidelines for this unique relationship, and especially because the longevity of it may have been unanticipated, parents are in a constant state of improvisation. These twelve families taught us that perpetual parenthood does not necessarily mean “the same old grind.” On the contrary, even in the face of perpetuity, parents change, the adult child

changes, the relationship changes, and the world around them changes. This is important, because outsiders, including professionals, may be quick to assume that there is a wearing down process that renders aging parents ready, or readier, to relinquish children to others. Although we know that there are a number of pressures that lead to the disintegration of parent care<sup>33</sup>, many of the families visited demonstrated an opposite process: of renewal, reconnection, and escalating commitment to care.

Several factors appear to contribute to this phenomenon. First, these sons and daughters with developmental disabilities are still *developing*. They are learning new skills and finding new ways of expressing themselves. Their personalities are deepening and expanding. Their relationships with others are strengthening. In some cases, a mellowing of behaviors has made them more manageable, even as their parents have become more frail. We recall Bill Stevens whose parents feel they are just getting to know him. We recall Kenneth Richardson whose parents were able to bring him home full time after years of institutionalization. And we recall Olivia Mandel, who is blossoming in a circle of friends also enjoyed by her parents.

Second, aging has liberated these parents from other responsibilities, allowing them more time to care for and enjoy their children. Parents once overwhelmed by the multiple responsibilities of work, caring for other active children, and caring for a child with a disability, can now focus more attention on that child. In some of these families, the retirement of the father allows him time to reconnect with his child, and at the same time, liberates the mother who can leave the house with more frequency and peace of mind.

Third, many siblings, who once represented a combination of dependency and support to their parents, have become an increasing source of support as they have matured into adulthood. Even grandchildren become part of the support system. The DeWitt family is a strong example of expanded support through the passage of time.

Fourth, as stated earlier, children with disabilities are a source of companionship, if not instrumental, and sometimes even financial, support to their aging parents. The reciprocity evident in the Strauss and Yordy families illustrates the complexity of family needs and dynamics in Double Jeopardy families.

Finally, the formal support system has become more responsive to the needs of these families. Most families attributed their capacity to “hang in there,” at least in part, to the support provided by sheltered workshops, transportation services, case managers, respite, and in-home care.

These families taught us that perpetual parenthood has its own stages across the life course. We cannot effectively serve aging families nor help them plan for the future until we understand these changes. We must also acknowledge the possibility of an escalation, rather than deterioration, of commitment over time. Aging families planning for the future may do so at their lowest state of readiness; for some, perpetual parenthood has become a mission, rather than an albatross.

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<sup>33</sup> See Essex, et al (1997); Krauss and Seltzer (1999); Hayden and Goldman (1996); Seltzer, et al (1997).

## **Chapter 25 The Sibling Question**

The futures of Double Jeopardy families are only as predictable as the expectations and intentions of extended kin, who have the potential to absorb at least some part of the care shift. Siblings are the most obvious source of continued informal care, but the sibling question is an extremely complicated one. First, societal expectations about sibling responsibility are even less clear than expectations about perpetual parental responsibility. Second, family discussions about sibling obligation are extremely sensitive; open discussions appear rare. Parents find themselves not wanting to either put children in positions of making promises they can't or don't intend to keep or of disappointing parents with frank reluctance to make promises at all. Sometimes parents operate on assumptions about the future role of children and seek no discussion.

The twelve families we visited represent a very broad spectrum of likely sibling involvement in the family's care shift. One family had no siblings at all, while another had many siblings, though none able to assume care. The only sibling in one family had a child with a developmental disability herself. In another family, a sibling had committed to making her life's work the caring for individuals with developmental disabilities, including her brother and sister. Some families have siblings nearby, while other families have siblings scattered across the continent. Some families have had clear discussions, while others have avoided them. In at least one family, a parent's expectation about the future involvement of a sibling was contradicted by other information.

It is evident that the care shift can be shared by the formal system and extended kin, particularly siblings. Effective planning and programming can maximize the support of family and the continuity of care, through a formal-informal partnership benefiting all. Ohio's Double Jeopardy program has addressed the sibling issue by offering planning education to siblings. More efforts like this are necessary to establish a role for siblings and to facilitate sibling involvement in the planning process. At the same time, the service system will have to develop family support programs geared toward siblings and their range of involvement, from co-residential support, to long-distance support, to guardianships, to social and recreational roles.

## **Chapter 26 Facilitating Individual and Family Planning for the Care Shift**

If future-focused family discussions with siblings are sensitive, discussions with the individual with a disability may be excruciatingly so. Yet maximum involvement of the individual is vital to self-determination. Again, the related range of experiences in these twelve families was wide. Clearly, SaraJane Norman cannot participate in discussions about her future; at the other end of the continuum, George Strauss can understand his choices and articulate his preferences, even when the discussions are emotionally difficult.

For individuals and families to make good plans for the care shift, they need information, support, and time. Again, Ohio's Double Jeopardy program and related programs across the state have made important headway. The very existence of this program has contributed to mainstreaming the notion and importance of planning; planning should become as normative a part of the family experience as accepting services or participating in support or recreational groups.

The twelve families we visited also represented a wide range of planning behaviors, from no planning at all, to complete legal and financial planning with open family discussion. Among the obstacles to planning we identified were emotional reluctance, lack of information, misinformation, and a sense that the timing was not right. Some families regarded the system redesign with suspicion; others expressed a concern about safety issues in some of the supported living arrangements. Most believe that their current arrangement is superior to any alternative; this makes pre-crisis placement unappealing and most share the “as-long-as-possible” goal of the Stevens family.

## **RECOMMENDATIONS FOR FURTHER RESEARCH AND DATA COLLECTION**

As we have noted repeatedly, Ohio does not have needed data to produce desired estimates, and we have had to rely on estimates based on national data. To produce an Ohio-specific and Ohio-sensitive analysis of the scope of Triple Jeopardy, we recommend the following:

1. Implement a uniform, state-wide system for organizing waiting list data.
2. For individuals and families known and served, as well as for waiting lists, gather demographic data that include specific ages and living arrangements of individuals, parents, and siblings. Identifying caregivers age 60+ in the PICT instrument is a good beginning, but as a very broad age group, it tells us very little, and as a non-representative sample, current PICT data can only hint at age distribution issues.
3. Conduct a study to identify hidden families, perhaps in collaboration with the Department of Aging, using a representative sample of Ohio counties.
4. Identify the care settings of the unserved individuals age 60 and older. It is important to understand how their dual needs related to aging and MR/DD are being met.
5. Develop a universal system to document the numbers of once-hidden Double Jeopardy families who are made known to the system at a point of crisis. These data will help us to estimate and project the size of the hidden family population.
6. Conduct a study to explore the current and future roles of siblings. This is a critical, unanswered issue with a profound effect on the scope of Triple Jeopardy.
7. Develop a demonstration project to enhance and support the role of siblings and other informal caregivers.
8. Explore ethnic patterns in informal care. Given Ohio’s changing ethnic profile, demographic data related to ethnicity are needed.
9. Conduct a demonstration project to integrate aging and MR/DD services in families with two-generation needs for long-term care.

## CONCLUSION

Even given data limitations, we can say with confidence that the state of Triple Jeopardy is a reality. Ohio has thousands of individuals with developmental disabilities living in precarious arrangements with aging caregivers, in a state unable to meet *existing* need. The impending care shift and cost shift will have an impact on not only the MR/DD population, but on all those needing long-term care in our aging communities. The demand for direct care providers alone will be staggering, no matter how we pay for it. Ohio has been a leader in consumer-directed care in both aging and MR/DD, and the impending care shift compels expansion of consumer-directed programs that incorporate compensated family care. Inevitably, the state and its counties will have to meet increased demand for services brought on by the care shift. The twelve families presented in this report demonstrate the complexity of that challenge. No matter which estimates about scope we use, our reality is that we are not ready. System redesign has been one step in the right direction. The state's continued challenge will be to join with individuals and families to develop programs and supports that promote continuity of care, quality of life, and fiscal health all at once. Doing so requires facing Triple Jeopardy head on, *now*.

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## APPENDIX A

**Source:** Braddock, D., Hemp, R., Rizzolo, M.C., Parish, S. and Pomeranz, A. *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities and Department of Psychiatry, The University of Colorado, 2002.

### OHIO

2000 State Population      11,287,827

Estimated persons with DD (@1.58%)	178,348	
Out-of-home placements (State of the States)	20,093	11%
Balance, at Home	158,255	
Estimated Living with Spouse (17%) (Fujiura, 1998)	26,903	15%
Own Household (15%) (Fujiura, 1998)	23,738	13%
Balance, Family Caregivers	107,613	60%
		100%

Estimated 60+ (@ 25.4%) (Fujiura, 1998)      27,334

Ohio +65 adjustment (Census Bureau, 1997)      1.07258

Family Caregivers (from above)	107,613	
Estimated Caregivers 60+ (OHIO 60+, @ 1.07258)	29,318	27%
Estimated Caregivers 41-59 (@35.08%) (Fujiura, 1998)	37,751	35%
Balance, Est. Caregivers < 41	40,545	38%
		100%