

Kathy Curran
I-Team WBZ (Boston)
November 13, 2009

Several state agencies and the Middlesex District Attorney's office are investigating disturbing allegations of abuse and neglect at a group home.

Danny Butler was found with bruises all over his body, black eyes and broken bones while in the care of a group home licensed by the state.

"He has down syndrome, he's lovable, he never had an enemy in the world until this," said brother Ed Butler.

But what happened and who's responsible are still unanswered questions that haunt Danny Butler's family.

The 61-year old was living at a group home in Dracut, a home managed by the Mental Health Association of Greater Lowell and licensed by the former Department of Mental Retardation.

On July 23rd, Danny was rushed to Lowell General Hospital because he was in respiratory distress.

Dracut Police weren't notified about Daniel Butler's injuries until he began having difficulty breathing and ended up in the hospital. That's when doctors and family members discovered all of the bruises and broken bones and called police.

Medical records show Danny Butler had multiple bruises, facial injuries, emotional trauma and possible sexual abuse.

Nancy Alterio, the head of the Disabled Persons Protection Commission says her agency had four allegations of abuse with this one victim.

According to reports obtained by the I-Team, one person at the group home said Danny fell out of bed, another said he pulled some dresser drawers onto his face.

One major problem with this investigation is that Danny Butler has been silenced by the trauma. Ed Butler says right now Danny can't communicate beyond yes or no, and as soon as the sun goes down he gets agitated and restless and he's very afraid.

Nancy Alterio said a lot of things can make it difficult to prove a case. When you don't have forensic evidence or testimony from victims or witnesses it's difficult to determine what actually did or didn't happen.

The Middlesex District Attorney's Office issued this statement:

"The victim in this case was in a vulnerable situation and suffered highly disturbing injuries. We are conducting an active investigation into what caused these injuries, who may be responsible and whether crimes were committed."

"It's tearing me apart. I don't know how many times I've cried up there watching him lay in bed. I don't want to see him hurt again and I don't want to see anyone hurt again," said Ed Butler.

All of the people involved in Danny's care and the residents at the group home are part of this investigation.

Danny Butler is currently at Tewksbury State Hospital recovering from his injuries.

A spokesperson for the Department of Developmental Services, formerly known as the Department of Mental Retardation, tells us the department has zero tolerance for abuse and if a case of abuse is found at a group home, the license is reviewed and steps are taken to make sure it doesn't happen again. The head of the Mental Health Association of Greater Lowell said his organization is cooperating with the investigation.

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REALITY-BASED COMMENTARY ON POLITICS AND POLICY IN MASSACHUSETTS AND AROUND THE NATION

Stop pending cuts to the already bare bones Disabled Persons Protection Commission [DPPC] - (+)

by: AmberPaw
Wed Apr 08, 2009 at 11:13:53 AM EDT

[subscribe]

Quote from yesterday's rally at the State House on behalf of the disabled:

COFAR President David J. Hart presided, pointing to two budget cuts under \$200,000 each that affected hundreds or thousands of disabled people, one to the Disabled Persons Protection Commission, the other to the Tufts Dental Facilities program. Hart showed pictures of a Jamaica Plain mansion recently purchased for \$900,000 by a non-profit provider as a likely example of a "bailout" and "sweetheart deal" for providers in the new state spending to open group home capacity for people to be transferred out of Fernald and the other three developmental centers slated for closure. "If governor Patrick steered favorable financing and a guaranteed state lease to a private for-profit company with \$395,587 per year CEO -- the newspapers and TV stations would be all over it. He might be impeached. Instead, the same basic insider deal minus the campaign contributions is presented to us as 'an investment.'"

For more info, go to: <http://www.cofar.org/>

As "JohnD" said, some are making a lot of money out of tough times. But the closing of Fernald, rather than saving money, is all about ideology - and profit to some.

The Disabled Persons Protection Commission is all that there is to oversee the care of adult cognitively limited citizens in group homes, or the frail elderly. If you suspect abuse, they are who must be called. See: <http://www.mass.gov/?pageID=dp...> cuts that mean that investigations don't happen because there are only two investigators for the whole state are going to cost lives, should this indeed occur.

My thanks to Senator Eldridge for the legislation he filed as a representative, to strengthen the DPPC: <http://www.mass.gov/?pageID=dp...>

Can someone clarify the status of this legislation, whether ongoing, refilled, or "dead" at the end of the last legislative session?

Also, the residents of Fernald and their families were promised a group home on the grounds of the Glavin Center. That promise turns out to be an illusion, even though there are no "cost savings":

Today your battle is about whether the families and individuals retain the right to remain in the homes that were theirs when the battles were won in the 1970s. The Department and myself, as recently as six months ago, made promises to people coming out of Fernald Center that they could live in state-operated homes on the grounds of the Glavin regional center, and the Glavin Regional Center would be there to support them, as an ICF. The people made that choice from Fernald in good faith; I believe they made a great choice. And now they are going to take that away some few months later, and I

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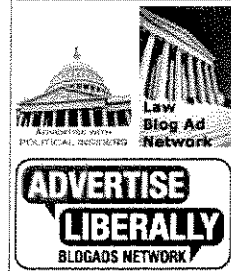


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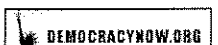
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in all good conscience tell you: That is not right. That is a promise broken. Help me out, and make this promise great."

Dr. Bacotti also disputed the claims of cost savings, but also their importance, "On the question of savings, I was talking to a budget aide to [leading Senator], I heard that it has been revised down to a 'budget neutral' No savings, probably a euphemism for 'likely to cost money.' The numbers are not important. Because it should not be about saving a few dollars. It should not be about saving \$41 million dollars. Stay focused. Yours are families with individuals that need you to advocate, and without you that advocacy just disappears, and so they will be moved by some bureaucracy without your input or theirs. You must advocate. It is not a choice; that is a moral obligation."

Will we collectively stand with Cain, over his brother's body, and deny that we are our brother's keepers?

In that Biblical Story, Cain murdered his brother and then took his brother's crops and so forth, and denied any wrong doing, stating that he was not his "brother's keeper".

Morally, it is the duty of adults to take care of children, and of the able to take care of those who cannot care for themselves. Without that axiom being upheld, the social compact falls apart, and there will not only be lives destroyed, but a return to the law of the jungle where in a socially Darwinian way, the predatory flourish, and those who need supports or act out of charity, are left to shoulder impossible burdens - and potentially founder.

To look away is to become an accomplice in the destruction of lives - and of the social compact itself. "Natural Law" as the Founding Fathers used the term relied on morality on the part of those in governance.

AmberPaw :: Stop pending cuts to the already bare bones Disabled Persons Protection Commission [DPPC] -

Tags: DPPC, Disabled Persons Protection Commission, Tufts Dental Facilities Program, COFA, Fernald, social compact, natural law, Eldridge, (All Tags) :: Add/Edit Tags on this Post

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Thanks for your post, AmberPaw (6.00 / 1)

You've tied a lot together here, particularly the issue of cuts to DPPC and DMR and the administration's broken promises concerning facility-based care.

As I've noted in another post I just filed today ('Our next legal step'), the Fernald League for the Retarded is asking for a federal investigation of the dramatic decline in conditions at the Fernald Developmental Center in recent months. We need to stop the Patrick administration in its race to the bottom in care for persons with mental retardation in Massachusetts.

by: Dave from Hvad @ Wed Apr 08, 2009 at 14:15:35 PM EDT
[Reply | none]

Group homes adjoining Glavin Center (6.00 / 2)

To clarify Dr. Bacotti's concern about broken promises, the four state-operated group homes next to the Irving Glavin Regional Center have been under the facility administration. Dr. Bacotti was involved in building them, and they are very well-designed and equipped homes. The two most recent ones are where he refers to broken promises. The homes will remain there, but if the Glavin Center is closed, residents, like hundreds more in the

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surrounding communities, will be deprived of the safety net of facility based 24-hour nursing availability, special needs dental care, employment, clinical and therapeutic specialists. Some things at the Glavin Center simply cannot be purchased in the community at any price: extended psychiatric hospitalization, the Tufts Dental Facilities Program, and physicians and psychiatrists trained in working with people with developmental disability.

The recent ARC study and Globe reports on young adults with DD still seeing pediatricians is very revealing on this kind of problem. Pediatricians have some training in communicating with patients who lack adult comprehension. But they aren't at all accustomed to working with adult bodies, people who are sexually mature, the variable mix of strengths and weaknesses of an adult with a disabling condition, or the psychotropic and anti-seizure medications taken by some people with DD. There are trained specialists in these areas, and federal law requires the state to have them at developmental centers as part of the licensing process. There are some employed by the state in the state-operated group home system, and some by the larger and more progressive provider organizations, but it isn't required under law, and in this economy, what isn't required is going to stop happening.

by: mzanger @ Wed Apr 08, 2009 at 16:09:38 PM EDT

[Reply | 6: Excellent]

Stop pendingt cuts (6.00 / 2)

Amber Paw your comments are spot on.

Caring for our mentally disabled citizens is our moral obligation.

Three plus decades ago the battle for the proper and humane care of the mentally disabled began. Fortunately a Federal Judge had the MORAL COURAGE (something that is obviously lacking today) to do what was right and took on the task of totally reforming the system of caring for these individuals. As this judge stated, a group with no political constituency. In doing so he created the greatest comprehensive care facilities for the mentally retarded and physically disabled. These centralized facilities are staffed with "experts" in caring for these unique people. Now the administration whats to dismantle what took years to build.

As the ARC points out in their article, private medical care for these individuals is inadequate. Irony since they are one of the greatest supporters of closing these institutions and throwing these fragile people out into an already overloaded community system that is also facing budget cuts and where competent medical care is scarce.

Their imaginary savings numbers give the impression that once these facilities are closed these people just disappear. Maybe thats what they are counting on. Its not a secret they use mortality rates in their projections.

As Dr. Bacotti points out, the state makes promises and casually disregards them. Must be part of that whole "trivial" thing. But we are suppose to trust that they are only interested in what is best for our family members. Right.

This administration doesn't know the meaning of the word morality.

by: ssurette @ Wed Apr 08, 2009 at 21:14:56 PM EDT

[Reply | 6: Excellent]

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Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green

Abstract

A review of the literature on cost comparisons between community settings and institutions for persons with mental retardation and developmental disabilities was conducted. We selected literature for review that was published in peer-reviewed journals and had either been cited in the area of cost comparisons or provided a novel approach to the area. Methodological problems were identified in most studies reviewed, although recent research employing multivariate methods promises to bring clarity to this research area. Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified. Implications are discussed in light of the findings.

The significant growth of community-based services has given rise to a dramatic shift in how services, especially residential services, are provided to people with mental retardation. As community-based services have expanded relative to institutions, aspects of costs, efficiency, and outcomes have grown in importance to practitioners, policy makers, and researchers (Braddock, Hemp, & Howes, 1986, 1987; Braddock, Hemp, & Fujiura, 1987; Campbell & Heal, 1995; Felce, 1994; Harrington & Swan, 1990; Mitchell, Braddock, & Hemp, 1990; Murphy & Dattel, 1976; Nerney & Conley, 1992; Rhoades & Altman, 2001; Stancliffe & Lakin, 1998). Despite the reduction in the number and size of large facilities that accompanied the increase in community-based residential services, large facilities are still with us. Tracking of facility trends shows that there are still more than 250 facilities nationwide with 16 or more beds serving nearly 48,000 individuals, 80% of whom are classified as having either severe or profound mental retardation (Prouty, Smith, & Lakin, 2001; Lakin, Prouty, Polister, & Kwak, 2001; Smith, Polister, Prouty, Bruininks, & Lakin, 2001). According to Polister, Smith, Prouty, and Lakin (2001), of the state-run facilities with 16 or more beds, 113 of them (nearly 60%) serve 150 or more individuals.

Several factors underlie the continued use of large facilities, including the institutional bias produced by the entitlements in federal Medicaid programs along with the pace of community expansion and the characteristics of the individuals themselves. For example, although community residential settings with 15 or fewer residents now number nearly 120,000 nationwide, waiting lists continue to grow and are a concern for policy makers and service providers. In studies of waiting lists, Davis, Abeson, and Lloyd (1997) and Lakin (1996) found between 52,000 and 87,000 individuals waiting for residential services, and nearly 65,000 were waiting for day programs. Overall, Davis et al. reported that 218,186 people were waiting for any type of services. Emerson (1999) has identified the same problem in the United Kingdom. Thus, the demand for community services for people with mental retardation and related developmental disabilities (MR/DD) has grown faster than the capacity of states to expand or create new community-based services.

The characteristics of individuals remaining in institutional facilities has also changed. Individuals still in institutions tend to be older and have more problems in daily living skills and in walking independently (Prouty et al., 2001). Although challenging behaviors are observed in both institutional

and community settings, more individuals remaining in large settings present challenging behaviors (Borthwick-Duffy, 1994; Bruininks, Olson, Larson, & Lakin, 1994). On average, about 47% of residents of large state facilities are reported to have behavior disorders, a statistic that has slowly increased since the late 1980s, from around 40%.

Although many have argued that institutions cost more than community settings (e.g., Heal, 1987), others have reported minimal cost differences (e.g., Schalock & Fredericks, 1990) or differences that favor institutions (e.g., Emerson et al., 2000). These different outcomes arise from the inherent complexities of research in this area, which is characterized by a heterogeneous population, complex funding strategies, methodological challenges, and substantial variability (cf. Butterfield, 1987).

Because a diversity of viewpoints exists, and because both settings are likely to coexist for some time, it is reasonable to review research in which investigators have examined the costs of these service models. This research area is rich in complexity and, although policy reports on costs and expenditures have appeared (e.g., Braddock, Fujiura, Hemp, Mitchell, & Bachelder, 1991; Braddock, Hemp, & Fujiura, 1987; Harrington & Swan, 1990; LeBlanc, Tonner, & Harrington, 2000), few reviewers of the cost literature have critically examined methodological elements of the available cost-comparison studies. This has added to the difficulty in drawing firm conclusions.

Although recent literature in this area has, to some extent, included evaluation of outcomes in addition to service costs, our primary focus in this article is on research in which costs were compared. This is not to denigrate the importance of outcomes; rather, our focus reflects the limitations of a single paper as well as the reality that although government officials and service elements typically desire to take quality and outcomes into account when planning programs, legislators often respond more directly to cost issues in funding decisions.

Considerations in Comparing Costs

Sources of Funds

Although services and supports for people with MR/DD are administered by states, the funds to pay for them are not limited to state funds; funds also come from local (e.g., county) and federal sources. The federal government plays a substantial role in states through the Medicaid Intermediate Care Fa-

cilities for the Mentally Retarded (ICF/MR) program and the Home and Community-Based Services (HCBS) Waiver program (Harrington & Swan, 1990; LeBlanc et al., 2000; Miller, Ramsland, & Harrington, 1999). Services for people with MR/DD in states are funded, to a large extent, through these two programs, which provide matching funds, with the proportions of federal and state contributions varying across the states (Braddock & Fujiura, 1987; Braddock & Hemp 1997; Braddock, Hemp, & Fujiura, 1987; LeBlanc et al., 2000; Lutsky, Alexi, Duffy, & Neill, 2000; Smith & Gettings, 1996). Currently, all 50 states have at least one active ICF/MR facility (Centers for Medicare & Medicaid Services, 2001), although not all ICF/MR facilities are large (i.e., institutions). Most large state-run facilities participate in the ICF/MR program, although there are large private ICFs/MR as well.

The HCBS Waiver program aids states in providing habilitative and other supports in community settings. Eiken and Burwell (2001) reported that

about three-fourths of (federal) Waiver expenditures are used to purchase long term care supports for persons with mental retardation and other developmental disabilities. In FY 2000, about \$9.3 billion of the total \$12.4 billion spent for HCBS Waiver services was targeted to persons with MR/DD.

This amount nearly equaled the \$9.9 billion spent on ICF/MR services in the same year. Since 1995, the average annual growth rate of HCBS Waiver services for people with MR/DD has been over 17%, whereas spending for the ICF/MR program has increased, on average, by less than 1%.

Cost Shifting

Results of early unpublished studies suggested that large facilities were up to 2.5 times as expensive as community facilities (e.g., Ashbaugh & Allard, 1983; Wieck & Bruininks, 1980). However, such conclusions are no longer valid because the analyses took place prior to the full operation of the HCBS Waiver program. Given the differences in the ICF/MR program and the HCBS Waiver program, there is the potential for costs to be shifted in complex ways. For example, whereas a placement in a large ICF/MR facility involves both state and federal funds, in varying proportions and at different levels across the states, not all community placements receive federal funds. Although some community-based placements are funded by both federal and state funds (e.g., under the HCBS Waiver), other services and supports are funded

solely by state funds, or are funded by complex combinations of personal/ private funds (including "entitlement" funds under Social Security) along with state funding.

In addition, the federal component of funding under both Medicaid programs varies from state to state, and for the HCBS Waiver, it varies based on what is contained in each state's Waiver agreement with the Centers for Medicare and Medicaid Services (CMS). Consequently, as fewer individuals are served in ICF/MR settings and more receive HCBS services, certain costs may be shifted to other Medicaid programs, or other state funds. According to Lutsky et al. (2001):

Per recipient Waiver spending fails to capture actual spending on Waiver recipients because it only accounts for a portion of their expenditures. HCBS Waiver recipients typically have some of their care, most notably acute care, home health, personal care, targeted case management, and adult day care, funded from the regular Medicaid program. (p. 8)

Cost Variation

Costs vary both *between* and *within* agencies and service systems, based on complex factors that affect them in several ways. Very similar services may vary widely in costs based on geography (e.g., urban vs. rural), unionization of staff, availability of professional staff, staff levels and ratios, ownership status (i.e., public vs. private), and other local factors in addition to characteristics of the consumers served. Such cost variation has been a consistent finding in the literature (Campbell & Heal, 1995; Mitchell, et al., 1990; Nerney & Conley, 1992).

Service costs also change over time as dynamic service systems constantly alter their complexion. For example, costs per resident in an institutional facility tend to rise when the most capable residents are removed and placed in community-based facilities. In addition, cost variation is typical both within and between service facility types. For example, in a study comparing costs in the United Kingdom, Hatton, Emerson, Robertson, Henderson, and Cooper (1995) reported average per person cost variations of as much as \$20,000 between institutional placements and specialized units *within* institutions and the same amount of variation among regular group homes. This phenomenon has also regularly appeared in the literature in America (e.g., Jones, Conroy, Feinstein, & Lemanowicz, 1984; Lakin, Polister, Prouty, & Smith, 2001; Nerney & Conley, 1992).

Staffing

Staffing levels and ratios have been identified as one of the major sources of cost differences across settings (Campbell & Heal, 1995; Felce, 1994). In addition to variability in staffing ratios across settings, there are clear-cut differences in salary and benefit levels. For example, public employees typically have richer compensation packages, and there may also be increased costs associated with the availability of professional and therapy staff. In short, staffing is not a stable variable with wide variability in compensation levels across settings and high rates of turnover (e.g., Braddock & Mitchell, 1992). Staffing levels and costs associated with staff, including recruitment and retention, vary depending on the needs and conditions, and the regulations in a particular setting (Larson, Hewitt, & Anderson, 1999). Therefore, costs associated with staff will prove to be a critical variable in all service models in the future.

Case Mix and Functioning Level

As community services expanded during the past quarter century, the average functioning level of individuals remaining in institutional facilities declined while, in general, their average age increased compared to the general population served by state agencies. These changes have taken place because fewer individuals overall were placed in institutional facilities, and special efforts were made to restrict the institutionalization of children (Lakin, Anderson, & Prouty, 1998). In addition, individuals with more skills and abilities are typically placed in community settings before individuals with more complex needs.

Thus, there are now stark differences in the populations served in community settings and those remaining in larger settings, typically public ICF/MR facilities. With respect to comparisons between these two groups, whether on costs, functional skills, quality of life issues, and so forth, population differences must be considered. In research terms, this process is known as *correcting for case mix* or *controlling for client mix* (Mitchell et al., 1990) and assures comparability based on characteristics of consumers. The importance of correcting for the severity of those served is underscored by Felce and his colleagues (Felce, Lowe, Beecham, & Hallam, 2000), who concluded that "costs of residential services in general have been found to depend on case mix, with the mediating variable being level of staff per resident" (p. 309). Taken together, the factors

of funding source, cost variation, staffing, and case mix are well-known and central to the cost-comparison literature. We now turn to a selective review of the literature showing how the research has addressed these and other issues in studies of service system costs in the MR/DD field.

Literature Selection

To show how the phenomena described above can affect conclusions about costs, we present a historical review of cost-comparison literature, highlighting studies that have gained prominence or address the issues raised herein. A comprehensive literature search was conducted using standard search strategies (Nerney, 2000) in several computerized databases (e.g., Medline, CINAHL, ClinPSYCH, PsychSCAN LD/MR) using keywords (e.g., *mental retardation, developmental disabilities, ICF/MR, costs, community, institution*) directly or in combinations to create Boolean searches. Two project members conducted literature searches using selection criteria requiring that identified documents (a) covered the MR/DD population; (b) included cost data or cost-related policy analysis; (c) were published or available since 1975; (d) were not case studies; and (e) were focused, at least in part, on residential services. Search results, including full identifying information, were saved electronically. Documents were then selected from these search results to form a document database. Documents that were selected were acquired, entered into the database, and stored in hard copy form. To assure that the two team members were selecting documents using the same criteria, we calculated average agreement at 88.5% on selections made from three large search result files. In addition, we regularly discussed search results and selections at project team meetings. Once acquired, the reference lists of documents were also searched for additional items not previously identified. Approximately 250 documents were identified and acquired in this way to form a working database.

Documents in this database were read and a smaller number selected for specific review if they (a) were published in peer-reviewed journals; (b) included community-institution cost comparisons; (c) were referenced in the cost-comparison literature; and/or (d) included a unique methodological element or approach, were frequently cited in the literature, or were illustrative of a specific historical point. Because of these stringent criteria, only a

small sample of the documents are specifically reviewed herein.

Research Review

Peer-reviewed articles were selected for review in this section to provide a historical glimpse of the cost-comparison literature over the past quarter century. Studies were selected that have a bearing on policy issues in the field, especially those related to cost comparisons. A summary of some of the selected studies is provided in Table 1. Because absolute levels of costs are less important here than comparative costs, no attempt has been made to adjust costs to a common fiscal basis. Therefore, caution must be exercised because the studies span a broad time period. Although comparisons *within* studies are possible, costs may not be directly comparable, on a dollar basis, *between* studies because of inflation and other factors.

Murphy and Dattel (1976)

In this early cost-benefit analysis, Murphy and Dattel reported that a community-placement program in Virginia produced an average net savings, across 52 residents, of \$20,800 per resident over 10 years (range = \$13,000 to \$29,000) or, on average, \$2,080 per person per year. They noted that most of these savings accrued to the state rather than to the federal government. Murphy and Dattel used complex data collected across system elements, and their often-cited 1976 study is not without methodological problems. One concern is that participants were not representative of the MR/DD population in two ways. First, over half of the 52 individuals studied (61.5%) did not even have mental retardation or other developmental disabilities, coming instead from a rural facility for persons with mental illness, thus also possibly underrepresenting urban and suburban settings. Second, participants were screened, and those who were not likely to succeed in community placement were excluded. Admittedly, Murphy and Dattel's main purpose was to assign costs to benefits of community placement and was not a formal cost-comparison study per se. Despite this purpose, the study is often cited in the context of cost comparisons. Further, with regard to methodology, the authors noted that "90 percent of the data on costs and benefits over the ten-year period were based on *projections*" (p. 169, emphasis added). The basis of these projections was, on average, only 8.5 months of community living. Al-

Table 1 Characteristics of Reviewed Studies

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Murphy & Datel, 1976	$N = 52$; MH = 62% MR/DD = 38% (moderate, severe, or profound); Ss placed from 4 institutions in VA	Average net savings of \$2,080 per year per client in community services. Subgroup showing no cost-benefit from community placement, most similar to current institutional population	Mixed, nonrandom, nonrepresentative (of MR/DD) sample. No correction for severity or case-mix Sample screened to eliminate potential community placement failures 90% of data derived from estimates (based on 8.5 months of community placement) No accounting for start-up or capital costs Different cost-aggregation methods across groups; relied on self-report cost data from community providers, including estimates, compared to accounting records for institutions Rater differences across groups Exclusion of three high-cost community cases
Jones et al., 1984	$N = 140$; 70 "movers" and 70 matched "stayers"; 85% severe or profound; drawn from Pennhurst facility in PA	Overall cost difference between community placement and public institution reported as \$6,886 per resident per year	No accounting for start-up or capital costs Small n -size in community setting No control for case-mix factors (i.e., community setting individuals not fully comparable to Fairview population) Few client characteristics provided to allow case-mix correction Day program costs were only estimates from budgets Community medical costs estimated from individual appointment records/documentation rather than billing encounter data
Schallock & Fredericks, 1990	Fairview facility (OR) with census of 1,084 compared to 4 group homes and an apartment program (combined capacity = 25)	Average annual per person ICF/MR costs = \$59,412 compared to \$53,635 in community settings; costs in two group homes most similar to Fairview population = \$60,615; equalizing raw costs for staff levels, community settings were more expensive	

(Table 1 continued)

Table 1 Continued

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Nerney & Conley, 1992	<i>N</i> = 375 living arrangements (group homes and nonfacility care) in 3 states (MI, NE, NH) compared with institutional costs	Institutional Care Rates (from records) Michigan: \$63,000 Nebraska: \$19,391 New Hampshire: \$28,411 Community Rates (corrected using 50% split on need) Michigan (non-ICF): \$47,359 Michigan (ICF): 48,487 Nebraska: \$25,778 New Hampshire: \$42,007 Overall cost savings in community of \$6,154 per person per year	Data collected at facility level; incomplete correction for case-mix factors Different cost aggregation methods across settings Extreme variability in costs Education and Medicaid-reimbursed costs excluded No accounting for start-up or capital costs
Knobbe et al., 1995	<i>N</i> = 11; all severe/profound with challenging behaviors; placed from state facilities into homes serving 3 individuals		No accounting for start-up and capital costs Estimates for community medical service costs appear to be underestimates
Campbell & Heal, 1995	<i>N</i> = 1,295 "observations" of clients living in all settings in South Dakota	Average annualized adjusted rates reported as: ICF/MR = \$55,560 ICF/15 = \$39,077 HCBS = 25,813 Community Training Services = \$21,210 Costs found to be associated with client characteristics, agency characteristics, funding source, staff: client ratio, and certain geo-demographic variables Average per person annual costs: \$115,168 in institutions; \$84,475 in community settings	Possible case-mix problems given loss of 29% of community sample Artificially high cost prediction may be due to use of aggregate vs. individual cost data
Stancliffe & Lakin, 1998; Stancliffe & Hayden, 1998	116 individuals moved to community settings and 71 remaining in institutions in MN		Medical and case management costs excluded from analyses Covariance methods may not have fully equalized groups

(Table 1 continued)

Table 1 Continued

Source	Settings and subjects	Cost outcomes	Factors limiting generalization
Emerson et al., 2000	86 adults in village communities; 133 adults in new residential campuses; 281 adults living dispersed housing schemes (group homes and supported living)	Averaged annualized per person costs (converted from pounds sterling to 1997-1998 dollars): Residential campuses = \$74,516 Village communities = \$71,604 Dispersed housing in community = \$85,852	Possible bias in at least one measure selected as a covariate Cost aggregation methods differed across settings No accounting for start-up or capital costs Overall system of services in UK may not be directly comparable with United States Non-random sample with relatively few exemplars of each model of service

Note: Because the study by Rhoades and Altman (2001) is not strictly a comparison study and the authors use a national database, it is not included in the table. MH = mental handicap. MR/DD = mental retardation/developmental disabilities. S = subject. ICF = Intermediate Care Facility. HCBS = Home and Community Based Services.

though most subgroups showed some cost-benefit, the one group that did not show cost-benefit was the most similar to the current MR/DD institutional population.

Jones, Conroy, Feinstein, and Lemanowicz (1984)

This widely-cited cost-comparison study was conducted as part of the court-ordered Pennhurst Center (Pennsylvania) depopulation effort. In this study the authors reported an average cost difference of between \$6,500 and \$7,000 in favor of community residential facilities. Despite many citations in the literature, the study does not appear to have generated much critical scrutiny. At the time of the study, approximately 85% of the population of the institution was labeled as having either severe or profound mental retardation. Cost data were compared between a matched sample of 70 "movers" and 70 "stayers." Data on six types of service costs were collected: (a) residential, (b) day program, (c) entitlement (i.e., public assistance levels), (d) case-management costs, (e) medical costs, and (f) other costs. Because Jones et al. collected additional information on costs, their study extends an earlier matched comparison study of behavioral change (Conroy, Efthimiou, & Lemanowicz, 1982).

Despite the prominence of the Jones et al. (1984) study in the literature, there are several methodological problems that may compromise the generalization of findings. Five are cited by the authors: (a) the Pennhurst dispersal was under a court-order and was, therefore, unlikely to have a normative cost structure; (b) subjects were not randomly assigned to groups; (c) all community placements served only 3 or fewer individuals; (d) self-report data on costs from providers in community residential facilities were used; and (e) medical costs were not fully enumerated. In addition, the data-collection design allowed for different methods of data collection across groups. At Time 2 (postrelocation) in this study and its precursor (Conroy et al., 1982), data for 40 of 70 movers (57% of those who moved to community facilities) were collected by "county workers," whereas this was *not* the case for stayers (i.e., those who remained in the institution). Data for stayers were collected by a team of trained workers who used teams of professionals as respondents. Furthermore, those who collected the behavioral data at Time 1 were not the same as those who collected the data at Time 2 for any subjects. Thus, raters were different between Time 1

and Time 2 and, for 40 out of 70 movers, were different from those rating all of the stayers at Time 2. In addition, as the authors stated, the interrater reliability of the behavioral data-collection instrument, the Behavior Development Survey, "has been shown to be barely adequate" (Jones et al, 1984, p. 306). Similar problems in methodology appeared in the collection of cost data.

For example, the authors did not explicitly examine the extent to which the different cost-estimation methods in the community and the institution may have yielded systematic biases in the data. In the community, costs were obtained by phone contact, with some costs being based on *estimates* made by one administrator in a county; these estimates were then applied to all individuals in that county. In the institution, by comparison, the operating costs were derived from state billing rates and examination of financial records. These differences in cost-aggregation methods, especially the reliance on broadly applied estimates in community settings, raises the possibility of systematic error. It is noteworthy, given the problems delineated here, that the authors themselves noted difficulties in making valid cost comparisons between community settings and institutions, including the difficulty in capturing costs, the heterogeneity of settings, and the fact that costs can be shifted between the state and federal governments.

More problematic in the present context is that the authors identified "three people living in community facilities with extremely high costs (\$77,578, \$103,679, and \$104,565)" (p. 308) and excluded them, arguing that they were statistical outliers. It is not uncommon for investigators conducting fiscal analyses in human services to find that a small segment of a population accounts for a proportionally large share of costs. Extreme values such as these likely represent *real* costs, despite the fact that in a *statistical* sampling distribution they appear as outliers. Excluding such data may have seriously skewed the cost findings. A better strategy would have been to analyze the data with the so-called "outliers" left in the dataset and then reanalyze the data with the outliers removed, thus allowing comparison of the overall effect of such cases.

Schalock and Fredericks (1990)

In a study comparing the Fairview facility in Oregon with four group homes and an apartment program, Schalock and Fredericks (1990) reported

an average cost of \$59,412 in the ICF/MR institutional facility compared to an average cost of \$53,635 in community residences. They attributed the average cost difference primarily to staff salary levels and noted that if corrections were made to equalize salary levels, the institutional facility would actually have been less expensive. Certain methodological problems were noted in this comparison as well.

For example, of the 1,048 individuals in Fairview at the time of this study, most had profound disabilities and fewer than 100 (< 10%) were school age, yet all of the community settings but one provided services to children. Furthermore, two of the comparison group homes provided services to children with mild mental retardation and emotional problems or disturbances. When considering only the two group homes serving residents who were most similar to the Fairview population, the community settings are found to be more expensive than the institution (*without* correcting staff salaries). One of these group homes served individuals with severe motor and ambulation problems who were incontinent and who, with the exception of one individual, needed to be fed by a staff member. The other home served children with profound mental retardation, some ambulation problems, and challenging behaviors. The average costs in these two facilities was \$60,615, or slightly more than the Fairview average cost. These authors concluded that:

These data present some troubling facts, especially for staunch advocates of deinstitutionalization. A general conclusion can be drawn from these data that, for individuals with challenging behaviors, residential costs within the community cost approximately the same as institutional services in Oregon, *given the current salary rates of institutional and community residential staff*. When these data are extrapolated, to equalize staff salaries between the institution and the community residence, the conclusion must be drawn that large institutions are, in most instances, less expensive than community residences for these challenging populations. (p. 283, emphasis in original)

Nerney and Conley (1992)

In this large-scale analysis of costs in regions of 3 states (Michigan, Nebraska, and New Hampshire), Nerney and Conley (1992) compared institutional costs and costs in community-based settings (including ICF and non-ICF group homes in Michigan). An array of cost data were collected from community settings, including direct-care and family-care payments (costs of care givers' operations/administrative costs, transportation costs,

medical/clinical costs (other than those paid by Medicaid or other third-party payers), day program costs, and other costs. Data were not collected on educational costs or Medicaid-reimbursed health care costs. Data on institutional services in these regions were collected from overall state cost reports. The institutional data were not collected in the same way as the community cost data (i.e., state developmental disabilities offices provided the rates), a methodological problem shared by much of the research in this area.

The overall costs of services to community-based individuals in the specified regions of Michigan, Nebraska, and New Hampshire were \$38,098, \$19,391, and \$28,411, respectively, compared to state rates for institutional care, which were \$63,000, \$32,000, and \$72,000, respectively. The community rates in this study, however, include *both* facility (i.e., group home) and non-facility (i.e., apartment, family, and foster care arrangements). Taken separately, and partially corrected for case mix by examining the 50% of settings with "high need" individuals, the differences between group home rates and institutions in Michigan were reduced to \$15,641 (non-ICF) and \$14,513 (ICF); in Nebraska they were \$6,222; and in New Hampshire, \$28,993. Factoring in the Medicaid medical costs and applicable education costs would further attenuate the reported community-institution cost differences.

The interpretation of these findings remains difficult for several reasons. First, data were collected at the level of *facilities* rather than *individuals*. It is likely that there are substantial differences, in each of these 3 states, between the population that resides in their community group homes and the population residing in their institutional settings. It is unlikely that the level of need analysis (a 50% split) fully accounted for such variability (i.e., fully corrected for case-mix factors). Second, as noted, the procedures for aggregating costs differed between the community settings and the institution, and certain costs, as the authors noted, were excluded (e.g., health care costs covered by Medicaid or start-up and capital costs). Third, although the Nerney and Conley (1992) provided separate estimates, the aggregation of all community settings (i.e., facility and nonfacility community settings) de-emphasizes the cost differences *within* community settings. That is, they reported "enormous" variability both within and between states. For example, in Michigan, costs in 11 community place-

ments were under \$10,000, whereas costs in 4 others were over \$60,000.

In accounting for the differences between community and institutional placements, Nerney and Conley (1992) noted that staffing was a primary variable, given that between 50% and 75% of all of the program costs are associated with staffing. For example, they noted that a substantial portion of the differences in costs between Michigan and Nebraska could be directly attributed to a staffing ratio in Michigan that was 1.62 times higher than in Nebraska.

Knobbe, Carey, Rhodes, and Horner (1995)

Although employing a very small sample ($N = 11$), Knobbe et al. reported a more complete cost-aggregation methodology than is typical in this area. Similar to Schalock and Fredericks' (1990) work, all of the participants had either severe or profound mental retardation and exhibited challenging behaviors and/or mental health problems, thereby providing an interpretive link to current institutional populations. A strength of the Knobbe et al. study is that it is longitudinal; the authors followed the participants who moved from large centralized state facilities to community settings of three individuals each (thereby avoiding case-mix problems). These authors aggregated costs in 16 distinct categories, between 1988 and 1990, including food, medical, utilities, administrative costs, staff training, transportation, insurance, gas/vehicle maintenance, and others. Unlike Jones et al. (1984) and Nerney and Conley (1992), community costs were collected by Knobbe et al. in a way that was similar to how institutional costs were collected. They reported an average yearly cost per resident for the 11 individuals in the community during 1990 as \$111,123 compared to their last year in the institution, which cost \$117,277 (adjusted for inflation). The difference in costs across the settings was \$6,154.

With regard to cost shifting, there was a rather large discrepancy between medical costs in the two settings, with institutional medical costs being more than five times greater than costs in the community (\$10,939 vs. \$2,144, respectively). The estimate for medical costs in the community settings is low considering health care cost findings in this population. For example, interpolating an annual cost for health care services, for 1990, from available literature (e.g., Adams, Ellwood, & Pine, 1989; Kronick, 1997; Kronick, Dreyfus, Lee, & Zhou, 1996)

suggested that a reasonable annualized estimate for all health care costs (i.e., inpatient and outpatient costs) for this population would have been between \$4,000 and \$4,500, which would account for much (about 38%) of the community versus institution cost difference found in this study.

Although Knobbe et al. (1995) employed a commendable methodology for aggregating costs, we note that neither start-up costs nor capital costs were included in the cost estimates. Nevertheless, these kinds of expenditures are real costs associated with developing community settings and, arguably, should be amortized and entered into the cost-comparison research. Mitchell et al. (1990) noted this issue in their review and commented that it is possible that such costs during rapid deinstitutionalization periods actually cause costs to rise sharply and then return to lower levels. In most of the studies reviewed herein, none of the authors accounted for either community or institutional capital costs or community start-up costs nor was there any correction for costs necessary to pay for state-operated regional and community offices that would not be necessary in an institution-only system.

Campbell and Heal (1995)

Campbell and Heal (1995) employed complex statistical modeling techniques to predict costs of services attributable to facility location, size, funding source, and level of client functioning. They reviewed the literature and indicated that the results of many cost-comparison studies can be challenged because of (a) the difficulty in aggregating costs equitably across community and institutional settings and (b) the lack of comparability in the institutional and community-based groups with respect to functioning level and care needs (i.e., case mix). In their 1995 study, these authors endeavored to address these problems.

Campbell and Heal (1995) examined 1,295 observations in South Dakota of individuals of all ages in 79 service groups, which were combinations of different provider agencies, funding sources, and residential service types. Data were collected on average daily costs that were comprised of seven cost centers (administration, support, room and board, etc.); in addition, the analysis included the average daily reimbursement rate for these services as well as staff-to-client ratios. The statistical analysis linked these data to characteristics of service location, agency characteristics, client characteristics, and service funding class as well as to a set of other

demographic variables (e.g., city population, county unemployment rate). A substantial portion of individuals in community settings (29%) were excluded from consideration for various reasons, whereas all but 2 individuals in the two institutions represented were included.

In the analysis, mean average daily costs for the different funding classes, adjusted for community, agency, and client characteristic variables, were (annualized): \$55,560 (ICF/MR); \$39,077 (ICF/15, i.e., a 15-bed ICF/MR facility); \$25,813 (HCBS); and \$21,210 (Community Training Services). In a related analysis staff ratios were found to be significantly higher for the ICF/MR settings, which accounted, in part, for the cost differences. Still, the difference across ICF settings (i.e., ICF/MR vs. ICF/15) is striking and suggests that different factors may be included in the cost bases. In addition, certain geodemographic variables (city unemployment rate, population size), along with client functional and behavior characteristics, predicted over 73% of the variance in costs. Adding provider characteristics (e.g., facility size) and funding source (ICF/MR, ICF/15, or HCBS) increased prediction to over 90%. Thus, a great deal of the variability in costs was associated with (a) provider and client characteristics (clients with more intense needs required more expensive services), (b) funding sources, and, interestingly, (c) characteristics of the locale. This last finding echoes the large cost differences across states that was reported by Nerney and his colleagues in the 3 states they studied (Michigan, Nebraska, and New Hampshire).

Exclusive of the institutional placements, Campbell and Heal (1995) found that community services costs bore a U-shaped relation to agency size, with large and small agencies being *more* costly than intermediate-sized agencies. This study, although analytically complex, provides no direct comparisons of costs across comparable groups; rather, the authors sought to predict costs (and other variables) based on a wide assortment of data. Large-scale studies such as this one are important and complement controlled group comparison studies.

One finding of special interest in the Campbell and Heal (1995) study was the strong predictive nature of client characteristics on costs. This finding is in juxtaposition with certain earlier findings. For example, Ashbaugh and Nerney (1990) concluded that client characteristics were *not* related to expenditures. Stancliffe and Lakin (1998) reported

a similar lack of relation between expenditures and client characteristics. The finding of a relation by Campbell and Heal, however, is important, because predicting 65% of the variance in costs shows that client characteristics *do* matter in service costs.

Stancliffe and Lakin (1998) and Stancliffe and Hayden (1998)

In these two studies, both conducted at the University of Minnesota, the authors drew their participants from 190 individuals enrolled in an ongoing longitudinal study. Expenditures and outcomes for 116 individuals with severe and profound cognitive impairments following movement to community settings and 71 individuals who remained in institutional facilities were studied. Stancliffe and Hayden (1998) followed the 71 individuals who did not move to community placements. Because cost analysis is rather secondary in the Stancliffe and Hayden study, our focus here will be the study by Stancliffe and Lakin (1998) in which "movers" and "stayers" were compared.

Although Stancliffe and Lakin (1998) made comparisons based on residential costs as well as total costs (residential costs + day program costs), comparisons between community and institutional settings were only conducted on total costs due to the aggregation methodology. These comparisons were reported for both raw and adjusted data using resident:staff ratio as a covariate, based on staff members available on weekday evenings. Stancliffe and Lakin reported significant differences in both raw and adjusted average daily total expenditures between community and institutions. Costs for residents in community settings (annualized: \$84,475) were 36% less than costs for residents in institutional settings (annualized: \$115,168).

Some of the problems identified in this research area, such as case-mix issues, appear to be resolved by the use of statistical analyses using covariates. However, taken together, statistics from both of these articles (Stancliffe & Hayden, 1998; Stancliffe & Lakin, 1998) suggest that certain selection factors may still have been operating that affected the outcomes and conclusions. For example, it appears from the data that a behaviorally challenging group may have been initially overlooked for community placement, requiring the state to develop public community ICF/MR settings. In addition, Stancliffe and Hayden presented statistics on therapy use in the severs group, suggesting that many of them had severe physical dis-

abilities. It is possible that some of these differences were not apparent in significance testing due to the reactivity of certain measures (e.g., using the ICAP Broad Independence score as a measure of adaptive behavior).

In addition, one of the variables used as a covariate, resident:staff ratio on weekday evenings, may have unduly penalized the institution relative to the community sample. Differences in staffing ratios across the day may simply be a proxy for differences in setting characteristics. For example, it is likely that the assessment of *overall* resident:staff ratios would have attenuated setting differences because in ICF/MR settings, there are many therapists available during the day that cannot be counted on weekday evenings. In an ICF/MR setting with residents who have multiple disabilities and restricted functioning, many resident training programs are likely to be active during the day, when specialized staff members are available to carry them out.

It is also the case that staffing levels in public ICF/MR settings that are slated for downsizing or closure may not be representative of typical staffing ratios. It is likely that, due to civil service rules, unionization, and so forth, that a lag exists between the reduction in census and the reduction in staff. In the studies conducted by Stancliffe and his colleagues, data were collected during a 4-year transition period as staffing levels were adjusted down in the institution and up in the community to accommodate the shift in consumers. Because staffing reduction in institutional settings almost certainly proceeds slower than staffing up in community settings, staffing ratios in these studies may be somewhat suspect and, as a covariate, are likely to have affected many of the analyses.

Finally, the exclusion of medical, case management, and capital costs no doubt affected the comparisons. We have already addressed the issue of the medical costs shifting from ICF/MR costs to other sources (e.g., private insurance, Medicaid fee-for-service). However, given the complexities of the community-based population described in these studies, it is not unreasonable to conclude that *additional* case management costs would accrue in the non-ICF/MR settings compared to the institution and community ICF/MR settings.

International Cost-Comparison Research

Although the main focus of the present review is the United States, there is a substantial body of literature from other countries that cannot be ig-

nored. This literature is, in some ways, strikingly different than the American literature. Felce (1994) reviewed the research on cost studies in the United Kingdom and explored what he characterized as a consistent finding that community services were more expensive than institutional services, in juxtaposition to the perception of many in America. For example, Emerson and his colleagues, who also studied costs in the United Kingdom, cited a previous meta-analysis that "adjusted costs . . . reported for hospitals [institutions] ranged across studies from \$799 to \$1,540 per week, whereas costs reported for group homes ranged from \$912 to \$2,750 per week" (Kavanagh & Opit, 1998, quoted in Emerson et al., 2000, p. 83, material in brackets added). Underlying the differences in cost-comparison research in the United Kingdom and America may be differences that exist in the service systems. For example, in America states share costs with the federal government in complex ways that promote cost shifting as state systems expand community systems relative to institutions. Because the costs that can be shifted under Medicaid programs differ and are not clearly understood by many, a perception may have arisen that there is no diseconomy of scale in smaller facilities. In contrast, because funding formula are less complex in the United Kingdom, it is assumed that community care will be more costly; in some ways just the opposite of the American view.

Still, Felce (1994) concluded that smaller community-based facilities offer the potential for increases in certain aspects of quality of life and that, in the long run, may be economically affordable. However, he cautioned that very small placements (i.e., smaller than 4) may not be able to maintain favorable costs structures if additional staff members are required based on increased needs of residents.

Recent work in the United Kingdom by Emerson and his colleagues (Emerson et al., 2000) found that costs associated with dispersed housing (i.e., housing that is integrated into existing communities) were 15% higher than those of residential campuses (i.e., institutions) and were 20% higher than village communities (i.e., clustered housing similar, in some ways, to regional centers and certain private facilities in America). After the authors adjusted for both adaptive behavior and challenging behavior, the annualized per person cost in 1997-1998 dollars (converted at £1 = \$1.63) for village communities was \$71,604; for residential campuses,

\$74,516; and for dispersed housing in the community, \$85,852.

In a multivariate study conducted by Felce and his colleagues in Wales (Felce et al., 2000), total accommodation costs were predicted from resident and setting characteristics, setting size, service processes, and indicators of quality. These researchers derived a two-factor regression solution predicting accommodation costs that included service model and client characteristics (Adaptive Behavior Scale [ABS] scores) that accounted for 51% of the variance in costs, adjusted $R^2 = .48$. Unlike the findings in America, costs in this model were found to be lower for institutions in comparison to community settings. Similar to some of the research conducted in the United States, client characteristics were important in predicting costs. According to Felce et al., the cost differences between service models were related to client characteristics, such that "costs tended to be higher for people with lower ABS scores within each service model... (and that) the consistent finding of UK research on deinstitutionalization is that community services are more expensive than institutional services" (p. 321).

At present, there is speculation as to what forces produce this juxtaposition of cost differences between the United Kingdom and the United States. Stancliffe, Emerson, and Lakin (2000) suggest that "one factor contributing to higher institutional costs in US studies may be that many US institutions have been downsized to the extent that relatively fixed institutional infrastructure and running costs are distributed over a small and diminishing population" (p. iii). This is precisely the interpretation offered by Braddock et al. (1991). This view is further echoed by Felce and his colleagues and has been voiced elsewhere in the literature. In addition, the work by Felce and his colleagues (2000) also assessed quality of life and noted that "This analysis provides additional evidence of a weak linear relationship between resource inputs and service quality, even after controlling for service recipient characteristics" (p. 323).

Rhoades and Altman (2001)

Using data from the 1987 National Medical Expenditure Survey (NMES), Rhoades and Altman (2001) used a different approach to studying costs in MR/DD services. In this survey, instead of taking the typical perspective of average aggregated costs from samples of individuals across settings, they de-

rived data at the *individual* level. That is, individuals were sampled, and then asked about their individual costs. Rhoades and Altman began by noting that despite the success of deinstitutionalization, problems remained, including (a) the more intense needs and, thus, associated increased costs, of those who remain in congregate care facilities and (b) the declining cost-benefit of community settings compared to institutional settings. These problems prompted the recognition that now that the field has effectively deinstitutionalized many individuals, "the remaining population, more likely to have multiple problems, is generally a population that would generate higher expenditures no matter where they are located" (p. 115).

From this perspective Rhoades and Altman (2001) conducted a multiple regression analysis that, among other things, predicted mean daily expenditures by several categories of person variables and facility characteristics. The authors extended the work done by researchers such as Campbell and Heal. Rhoades and Altman reported that:

The results of the multivariate analysis indicate, at a national level, what Campbell and Heal (1995) found in South Dakota. Facility characteristics, resident characteristics, and even community resources play a part influencing daily expenses for residents in facilities both large and small... The results also show that for persons with borderline, mild, moderate, or severe levels of mental retardation, it is more expensive to provide care in larger facilities. For individuals with profound mental retardation, the size of the facility is not a factor in daily expenses once the increased expenses for the level of mental retardation are considered. (pp. 123-124)

In a way, the Rhoades and Altman study (2001) was the beginning of the shift in the literature away from controlled comparison studies. Instead of using static comparisons to determine specific costs in a policy-making context, results of this study suggest that researchers should approach the problem from the perspective of the individual and identify the most favorable placement based on the characteristics of the person and the service setting together. The authors showed, for example, that resident characteristics were, indeed, associated with costs of care regardless of the setting. Perhaps even more interesting is the interaction with level of mental retardation such that "Persons with similar levels of dependence had different daily expenses, related to their level of mental retardation and, thereby, the ability to cooperate and communicate with caregivers" (p. 126). This work is important because the results suggest questions that relate specific needs of individuals to specific re-

quired services independent of the setting. Again, in the words of Rhoades and Altman:

It is important to understand how organizational type, resident characteristics, number and types of services, and location come together to influence expenditures in order to develop the necessary resources for proposed health care delivery plans. Examining expenses from the individual rather than the organizational perspective allowed us to examine this complicated puzzle in a different way. (p. 127)

In such a context the question: "What costs more, community or institutions?" or "Which type of setting serves an individual better?" is no longer the critical question. Adopting the approach implied by Rhoades and Altman (2001), it becomes clear that costs and expenditures are related to the needs of the person, the quality of services provided, the desired outcomes, and perceived satisfaction on the part of the individual.

A Word on Outcomes

Although we are aware that the issues of quality of services and service outcomes necessarily go hand in hand with costs, the empirical association between costs and quality is less established when a broad array of research findings are examined. For example, positive outcomes reported in the literature associated with deinstitutionalization and community-based services include increased choice (Stancliffe, 2001; Stancliffe & Abery, 1997), behavioral improvement (Kim, Larson, & Lakin, 2001), improved social interaction of certain segments of the population (Anderson, Lakin, Hill, & Chen, 1992), integration in rural settings (Campbell, Fortune, & Heinlein, 1998), and inclusion in various day-to-day activities (Campo, Sharpton, Thompson, & Sexton, 1997; Emerson et al., 2000). However, such positive findings need to be considered in relation to findings of increased mortality in community settings (Strauss & Kastner, 1996; Strauss, Kastner, & Shavelle, 1998; Strauss, Shavelle, Baumeister, & Anderson, 1998; see also Taylor, 1998), problems in vocational services and employment (Stancliffe & Lakin, 1999), and problems of Individual Habilitation Plan objectives and behavioral technology (Stancliffe, Hayden, & Lakin, 1999, 2000). Recent work has also highlighted problems in access, utilization, and quality in community-based health care and personal care for people with mental retardation and developmental disabilities (Knobbe et al., 1995; Larsson & Larsson, 2001; Walsh & Kastner, 1999). Emerson and his

colleagues (2000) identified higher rates of verbal abuse and relatively greater exposure to crime among individuals who lived in dispersed community settings. Finally, Felce and Perry (1997) reported that in the community settings they studied, staff members generally lacked organized approaches and skill sets to promote development in those living in the settings in which they worked.

Although the assessment of consumer satisfaction and quality of life has been reported often in HCBS settings, in other evaluation reports, investigators (e.g., Lutsky et al., 2000) have noted a set of specific concerns around quality of care, as did LeBlanc et al. (2000). As stated by Lutzky and his colleagues, these concerns include (a) difficulty in state monitoring of noninstitutional care because of their dispersed nature, an increasing problem as more HCBS placements have been created; (b) inexperience in monitoring noninstitutional care, in some states including a lack of regulations and licensing requirements; and (c) the potential impact of low provider reimbursement rates on the quality of care. In the words of Lutsky et al. (2000): "The effectiveness of licensing and regulatory requirements at ensuring quality of care is impaired if states do not sufficiently monitor compliance. However, monitoring quality of HCBS services may present greater challenges than monitoring quality in institutional settings" (p. 28).

It may also be the case that quality of care and quality of life differ across community and institutional settings in their importance to stakeholders. For example, as institutions increasingly provide services to people with severe and profound cognitive deficits, complex needs, challenging behaviors, and diminishing skills, concerns about quality of care may outweigh those of satisfaction. In community settings, on the other hand, with a more heterogeneous and able population, it may be that quality of life, satisfaction, and interest in self-determination takes on more importance. Thus, the assessment of both quality of care and quality of life, although related and important in both settings, may need to be adjusted for characteristics of the setting in which they are assessed.

Therefore, we agree with Emerson (1999) that outcome measurement be expanded beyond assessment of personal outcome measures, such as choice and community involvement, to include a greater emphasis on health and safety. As Walsh and Kastner (1999) have pointed out, health and safety outcomes have been underrepresented in the MR/DD

literature (cf. Hughes, Hwang, Kim, Eisenman, & Killian, 1995). Outcome measurement needs to include direct indicator and benchmark assessment of outcomes based on clear standards. For example, individuals with profound disabilities and multiple disabling conditions may benefit from measures evaluating (a) access to comprehensive health care services (primary, psychiatric, and dental care as well as ancillary services, including care coordination); (b) rates and status of abuse/neglect reports and investigations (including victimization in the community); (c) mortality review; (d) access and utilization of behavioral services; and (e) similar direct measures.

Discussion

In this review of selected peer-reviewed studies, we have documented the complexity of research examining costs of community and institutional service models and show how methodological problems affect conclusions. The work reviewed here spanned a quarter-century during which time the field was in constant transition. Early studies were designed simply to show the cost-benefit of community placements (e.g., Murphy & Dattel, 1976), whereas more recent work has highlighted the complex multivariate nature of the area and recognized the need to identify costs at the individual level (Rhoades & Altman, 2001). The shifting cost structures across settings during the period reviewed, and the heterogeneity of the population served, prompts the conclusion that the question "Which is less expensive, institution or community?" is the wrong one to ask. Rather, the questions that need to be asked revolve around the individual (i.e., What does this person need? Where is the best place to provide for these needs?" and "at what cost?").

The research reviewed here suggests, in several ways, that community placements are not inherently less expensive than institutions. First, there is an intrinsic lack of comparability between institutions and community settings. For example, community services include a diverse array of service types, ranging from minimal intermittent supports to residential and day program services, whereas institutions traditionally offer an established service package (e.g., ICF/MR services). Thus, only a part of the range of community services is comparable with the services received in a large ICF/MR. Researchers comparing costs need to assure that the service packages are comparable across settings, a

challenge given the inherent differences in these service systems. Second, during deinstitutionalization efforts, the ability to shift certain community costs to programs other than those administered by a particular MR/DD state agency will lead to reduced costs *within* that specific governmental division or authority. However, the overall cost to society may not be reduced. For example, medical costs within an ICF/MR are clearly part of the budget of the state MR/DD authority; however, when an individual moves to a community setting, medical expenses can often be shifted to another funding source (e.g., the component of state government that administers Medicaid health care benefits). Third, the apparent cost savings in community settings, to the extent that it is found, is often directly related to staffing costs. Results of the research reviewed herein suggest that the modest differences reported for community services are predominantly the result of lower staffing costs in privately operated community settings compared to state-operated settings. However, the lack of parity between staffing costs in institutions and community settings is not a desired efficiency. In fact, it is likely that any initial cost benefits claimed for community settings will be difficult to sustain as individuals with more complex needs are served in these settings. Further, over time, it is possible that the disparity between community and institutional cost structures for staffing will diminish as community workers and advocates strive to achieve parity in compensation with respect to state workers. Results of the present study suggest that the area of staff compensation deserves further study.

These elements of complexity in community-institution cost comparisons give rise to several recurring methodological problems. These problems include (a) the lack of comparability between groups based on biased, nonrandom, or convenience samples; (b) the lack of adequate case-mix controls; (c) differences in data-collection and cost-aggregation methods across groups; (d) the exclusion of critical categories of costs, such as medical expenses, case management, start-up, and capital costs; and (e) extreme variability in costs, cost shifting, and statistical-modeling problems.

These methodological problems limit generalization across settings. Three especially challenging methodological problems deserve special mention. First, few of the studies reviewed herein completely accounted for case-mix factors. Given the heterogeneity of the population of individuals with MR/

DD and the near impossibility for random assignment to residential settings, complex case-mix factors are always present. Longitudinal studies and multivariate studies using statistical controls (e.g., employing covariate methods) offer promise as long as care is exercised in the selection of variables. Ideally, covariates that include both cognitive and adaptive measures should be included, although this was not typical of the studies we reviewed.

Second, cost-aggregation methods varied widely over the reviewed studies. Often, the cost-aggregation method used in community settings was different than the way costs were identified in facility settings. In our review, researchers who employed more complex and complete cost-aggregation methods typically found smaller, if any, community-institution differences. In studies from the United Kingdom, which seem to be less susceptible to methodological artifacts (such as cost shifting or inability to estimate costs), researchers typically reported increased costs in community settings.

Third, elements of costs were routinely excluded in even the best studies reviewed here, sometimes because they were shifted to other funding sources and sometimes because the data were unavailable. In both cases it is not acceptable to assume that the effects of costs that are shifted or excluded are the same in the comparison groups. We have noted, for example, that many service costs are *built into* the ICF/MR model. The costs incurred for supporting community infrastructure for such costs cannot simply be excluded from the cost-comparison analyses. Related to this, an inherently difficult fiscal problem is the inclusion of start-up and capital costs incurred in community settings compared to long-term state ownership of institutional facilities. Excluding these categories of costs is not justifiable, and researchers need to identify methodologies that include these costs (e.g., Emerson et al., 2000). In conclusion, in nearly all of the studies reviewed, certain specific costs were excluded from the analyses, thus limiting the generalization of results.

From the cost studies reviewed here, it is clear that large savings are not possible within the MR/DD field. That is, the costs of residential care, regardless of setting, involve a specific amount of resources that vary, somewhat predictably, with staffing levels, client characteristics, and other variables as in the studies reviewed. These studies do not support the view that large cost savings are possible. In fact, researchers who conducted the studies re-

viewed here that employed more sophisticated and complete cost-aggregation methods tended to find the smallest differences across settings (e.g., Knobbe et al., 1995; Schalock & Fredericks, 1990).

Although this review provides a unique historical overview of research in this area, it is not without limitations. First, we restricted our selection of studies to those that were peer-reviewed and addressed the issues under consideration. We narrowed our selection to peer-reviewed studies for quality control reasons and because, for example, unpublished state-level reports might be especially susceptible to cost-shifting effects. A cursory review of many of these reports, however, suggested that their inclusion would not substantially alter our conclusions. Second, we did not directly review the outcomes literature, although, as we have noted, we believe it to be critically important in this field. Third, the scope of this work did not allow us to review cost comparisons made between different community settings, although published work is beginning to appear in this area and will prove to be more critical in the future. We believe that the methodological considerations presented herein will continue to be important as that literature grows.

In the final analysis, it appears that the costs of caring for people with MR/DD will be highly variable across settings and will vary with the characteristics of those served and the resources, especially staffing, devoted to serving them. Because this population ranges from individuals who are barely distinguishable in the general population to individuals who require high levels of sophisticated care, it is likely that a range of service models will continue to be needed. In the future, researchers who conduct studies that will best inform public policy are likely to be those employing multivariate methods to take such heterogeneity into account. As we have documented here, movement toward such research models is already underway.

Based on the analysis presented here, the choices made by governmental agencies about the relative mix of service types should include a consideration of consumer needs rather than being made solely on the basis of local service costs. It is also important to take into account the values of those who use the services.

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Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999

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Life Expectancy Project

Abstract: More than 2,000 persons with developmental disability transferred from California institutions into community care during 1993 to early 1996. Using data on 1,878 children and adults moved between April 1, 1993 and March 5, 1996, Strauss, Shavelle, Baumeister and Anderson (1998) found a corresponding increase in mortality rates by comparison with those who stayed behind. Shavelle and Strauss (1999) updated the study through 1996 and found similar results. The present study is a further update through 1999. There were 81 deaths, a 47% increase in risk-adjusted mortality over that expected in institutions ($p < 0.01$). As in the two previous studies, we found that persons transferred later were at higher risk than those moving earlier, even after adjustment for differences in risk profiles. The difference cannot be explained by the short-term effects of the transfer, and therefore appear to reflect an increased mortality rate associated with the less intensive medical care and supervision available in the community.

Key words: Community care, developmentally disabled, epidemiology, excess death rate, institutions, mortality, standardized mortality ratio.

1. Introduction

Budgetary constraints in the United States in general, and California in particular, have forced a re-examination of policies for caring for the developmentally disabled. Many states in the U.S. now have waiting lists for services, and only limited offerings once service is established. California is unique in that care for the developmentally disabled is an entitlement, mandated by the Lanterman Developmental Disabilities Services Act of 1969. The Act guarantees people with developmental disabilities the right to the services and supports they need to live like people without disabilities (Department of Developmental Services, 2001). A developmental disability is defined by the State of California as a condition arising prior to age 18, which is permanent and will affect the child's ability to care for himself/herself. Examples include cerebral palsy, autism, down syndrome and mental retardation.

Deinstitutionalization is a sensitive issue, with attendant philosophical and political considerations. It is often difficult to discuss the topic without emotional opinions being voiced and dogmatically defended. Because it can involve life or death, and extensive public and private financial resources, however, it is a necessary topic of discussion and inquiry.

California carried out a major deinstitutionalization during 1993-1996, with more than 2,000 children and adults with developmental disability transferred from state facilities to community care. Most were relocated to private group homes. Strauss, Shavelle, Baumeister and Anderson (1998) — hereafter, SSBA — analyzed the mortality experience of a group of 1,878 of these movers. There were 45 deaths in their April 1, 1993 to February 14, 1996 study period. This represented a 51% increase in mortality, relative to that of comparable persons living in state institutions. Subsequently, Strauss, Anderson, Shavelle, Sheridan and Trenkle (1998) reported on the causes of death, using information from the death certificates. Most recently Shavelle and Strauss (1999) — hereafter, S&S — analyzed 1996 mortality and found an excess mortality of 88%.

Investigation of the outcomes of deinstitutionalization has continued in recent years (Crichton, 1998; Stancliffe and Abery, 1997; Stancliffe and Hayden, 1998), but work on health-related outcomes remains limited. Mortality is one important measure of quality of health care, and has the advantage of being simple and unambiguous to measure (SSBA). Here we summarize of the mortality experience in 1997 to 1999 of the same group of subjects analyzed by SSBA and S&S, using the same methods. Our aim was to see whether the results in the earlier works held true over the more recent period. This study may shed further light on the issue because the subjects are free of the extra early mortality described as the “dislocation of moving” effect.

2. Methods

There were 1,776 subjects in the study at the beginning of 1997, the 1,812 considered by S&S less 36 who died in 1996. All movers left a state institution between April 1, 1993 and March 5, 1996. For the profile of the original 1,878 subjects with respect to functional skills, type of community residence, and other characteristics, see SSBA. The risk factors used for statistical adjustment were age, gender, mobility and self-care skills. SSBA described how these were measured. Deaths were found by matching the Client Development Evaluation Report (CDER; California Department of Developmental Services, 1986) data base with 1997-1999 mortality information from the California Department of Health Services (1999). The statistical methodology here was the same as that of SSBA and S&S. Briefly, we:

a. Used previous research that identified the factors related to survival of persons with developmental disabilities. In addition to the usual factors of age and sex, these were feeding and mobility skills (SSBA, S&S).

b. Used information on the factors to develop a logistic regression (Hosmer and Lemeshow, 1989) model to predict the probability of death given various patient characteristics.

c. Applied the model to the children and adults recently moved from institutions as follows: For each person calculate his/her "exposure time", the time in months from the beginning of the observation period to the earlier of (i) the end of the study period, or (ii) death.

d. Calculated each person's expected chance of death by multiplying the probability computed in (b) by their exposure time computed in (c). The sum of these values over various groups were the expected numbers of deaths.

A fuller description of the methods is given in SSBA and S&S.

3. Results

Of the group of 1776 subjects, 81 died in the 1997-1999 study period. Table 1 shows the numbers of deaths, number of person-years at risk, and mortality rate, both on an aggregate basis and broken down by year of move. The year-specific mortality rates show an increasing trend. In part, this reflects the fact that the highest functioning individuals tended to transfer first (details not shown here).

Table 1: Mortality Rates in 1997-1999 for 1993-1996 movers.

Group	Number of deaths	Total person-years at risk ^a	Mortality rate ^b
1993 movers	14	1331.6	10.5
1994 movers	27	1682.5	16.1
1995/6 movers ^c	40	2201.0	18.2
All movers	81	5215.1	15.5

^aTotal time between January 1, 1997 and December 31, 1999 (or until death of client) for the 1,776 movers.

^bNumber of deaths per 1,000 person-years.

^cBecause there were only 7 deaths to the group who moved in early 1996, this group was combined with the 1995 movers.

In Table 2 we compare the numbers of deaths to the expected number for comparable persons residing in institutions, taking account of age, gender, and functional skills. The ratio of the two is a standardized mortality ratio (SMR).

The 81 deaths corresponds to an SMR of 1.47, i.e., a 47% increase over what would be expected ($p < 0.01$; 95% confidence interval 1.15 to 1.78).

Table 2: Comparison of movers with the institutional population in 1997-99^a.

Group	Expected mortality rate ^b	Standardized mortality ratio (SMR) ^c	95% confidence interval for SMR ^d
1993 movers	10.3	1.02	(0.49,1.55)
1994 movers	10.1	1.55	(0.99,2.18)
1995/6 movers ^e	11.2	1.63*	(1.12,2.14)
All movers	10.6	1.47**	(1.15,1.78)

^aBased on data on all persons residing in state institutions at any time between January 1, 1987 and December 31, 1993.

^bExpected number of deaths (x 1,000) based on the Poisson model, divided by the number of person-years at risk.

^cThe ratio of the observed number of deaths to the expected number based on the Poisson model.

^dComputed as $SMR + 1.96 \cdot (SMR/E)^{0.5}$, where E is the expected number of deaths (Kahn and Sempos, 1989, p.101).

^eBecause there were only 7 deaths to the group who moved in early 1996, this group was combined with the 1995 movers.

*Significantly different from 1.0 at $p < 0.05$.

**Significantly different from 1.0 at $p < 0.01$.

Table 2 shows that the SMRs tend to be larger for the persons who transferred in the later years. Note that this trend has remained even after adjustment for risk factors (age, gender, and skills). The same trend was observed by SSBA and S&S for deaths in the earlier study periods.

The trend of increased death rates for persons who transferred later was likely due to those moving later having additional medical conditions or being more frail. Indeed it is reasonable to expect that those moved earlier would have been the most qualified and/or most willing to move. In addition, earlier movers may, if anything, be healthier than their data alone would indicate; that is, the available data may not fully capture the individual's mortality risk. Frailty, while a useful medical concept, is not explicitly available on the data base, and thus was not a variable in the logistic model.

In Table 3 we stratified the data (both deaths and person-years of exposure) into four groups on the basis of mobility and the use of a feeding tube. In contrast to the previous two studies (SSBA and S&S), the SMRs here were rather similar. Conversely, the excess death rates (EDRs) decreased sharply with increasing

functional ability. For example, the EDR was 36.5 per 1000 for group 1 (that is, 36.5 extra deaths per year for every 1000 persons), but only 3.1 extra deaths per 1000 for group 4.

Table 3: Observed and expected numbers of deaths in 1997-1999 among the movers, stratified by level of functioning.

	1	2	3	4	Total
Observed deaths	7	11	37	26	81
Expected number ^a	4.88	9.03	24.84	16.54	55.29
Standardized mortality ratio (SMR) ^b	1.43	1.22	1.49	1.57	1.47
Difference of mortality rates (EDR) ^c	36.5	10.0	6.5	3.1	4.9

^aExpected numbers are on the basis of institutional rates for comparable subjects.

^bObserved divided by expected number.

^cObserved mortality rate less expected mortality rate, per 1000 person-years.

1 = Persons tube fed and with no motor skills (does not lift head; no hand or arm use; does not crawl, creep or scoot; does not walk)

2 = Persons either tube fed and with some motor skills, or not tube fed and lacking motor skills.

3 = Persons not tube fed and with some, but not all, motor skills.

4 = Persons not tube fed and with full motor skills (walks well alone).

As in S&S we also compared the observed number of deaths in **institutions** with the expected number according to the model used. These were 251 and 260.46. Thus, as in the previous study, the model predicted the number of institution deaths with considerable accuracy. This may increase confidence in the validity of the model-based comparisons reported here.

Underlying **causes of death** from the California Department of Health Services are shown in Table 4. The data are provided in the form of computerized numerical codes according to the International Classification of Diseases, Ninth revision (Context Software Systems, 1995). There were 6 deaths due to cancer, compared to 4 of the 36 deaths reported in S&S and 0 of the 45 reported in SSBA. This is consistent with SSBA's hypothesis that the earlier selected movers tended to be the healthiest available at the time of moving. There were 17 deaths due to pneumonia, only 1 of which was aspiration pneumonia; previously S&S found 4 of their 8 pneumonia to be aspiration pneumonia. There were 5 externally-caused deaths, including 1 drowning and 2 homicides.

Table 4: Causes of deaths 1997-1999 (number of deaths in this category).

Viral infection (1)
Cancer of esophagus (1), larynx (1), ovary (1), kidney (1), or other (2)
Other metabolic disorder (1)
Mental retardation (5)
Other cerebral degeneration (1), or parkinsons (1)
Infantile cerebral palsy (7)
Epileptic seizure (2)
Other conditions of brain (2), central nervous system (1), or peripheral nervous system (1)
Hypertensive renal disease (1)
Acute myocardial infarction (2), or other ischemic heart disease (5)
Other heart disease (6)
Pneumococcal pneumonia (2), other bacterial pneumonia (1), bronchopneumonia (3), or pneumonia, unspecified (10)
Influenza (1), chronic airway obstruction (2), or aspiration pneumonia (1)
Disease of esophagus (1), gastric ulcer (1), duodenal ulcer (1), or other digestive disorder (3)
Other urinary system disorder (1)
Other congenital anomaly of heart (1)
Other congenital anomaly (2)
Convulsion (1)
Unknown (2)
Other and unspecified fall (2)
Accidental drowning (1)
Homicide by stabbing (1), or by legal intervention (gunshot) of police (1)

4. Discussion

Overall, the community death rate was 47% higher than expected for comparable persons living in institutions. This figure is lower than the 88% reported by S&S — which may have been due to a temporary overload of the community care system from the rapid deinstitutionalization — but similar to the 51% of SSBA. The differences between the excess death rates in the three studies were not statistically significant. Reasons for the lower mortality rates in institutions compared to other residence types have been suggested (Strauss and Kastner, 1996). These include: continuity of care, centralized record keeping, and immediate access to medical care.

As all movers had already been living the community for at least 9 months

prior to 1997, their excess mortality cannot be ascribed to short-term relocation effects. We therefore did not analyze mortality in terms of time since transfer.

There is evidence that these results are not artifacts of the model chosen. Firstly, the model-based expected numbers of deaths were very similar under a wide choice of plausible models (see SSBA). Secondly, as noted, the observed number of deaths for persons **remaining in the institutions** was close to its model-based expected value.

The methods used here are applicable to a wide range of social and policy issues. The approach is to compare observed and expected values, where the expected values are computed from a model calibrated to past, present or optimal experience. Applications could include the effects of:

- a. Variation in prison inmate reform measures on rates of residivism,
- b. Experimentation with welfare payments and work requirements on subsequent financial status, or
- c. Improved teacher training or incentives on student performance.

This is by no means an exhaustive list, and the reader will undoubtedly by now have mentally compiled his/her own list of (i) past social or policy issues that should have been more appropriately studied prior to widespread implementation, or (ii) future areas in need of study. Indeed a careful analysis of potential outcomes, costs and benefits, while given appropriate mention in the planning and “public hearing” stages of policy boards, is often the first casualty of partisanship, budget cuts, and expediency. This is unfortunate, given today’s often abundance of data, lightning-fast computers, and qualified personnel to perform the analyses.

Given the higher mortality rates outside institutions, it might be asked why deinstitutionalization was considered, implemented, and continues to this day. Among other reasons — we attempt to avoid political issues here — major factors include the long history of this movement, the fact that the evidence about increased mortality has only recently emerged, and increasing financial pressures on public agencies. We address each of these in turn.

The deinstitutionalization movement began many years ago, at the same time as efforts to “mainstream” the mentally ill. The 1962 book by Ken Kessey, “One Flew Over The Cuckoo’s Nest”, and the 1975 film with Jack Nicholson based on it, helped shape the public’s view of mental institutions. In the U.S. in the 1960’s, institutions were disparaged as “snake pits” and thought to offer little benefit to patients. A recent book by Michael D’Antonio (2004) describes the “dark era of institutionalization” in the 1940’s and 1950’s. The author chronicles a history of injustice and poor care at the Fernald School in Massachusetts, home to “the feeble-minded and disabled.” The school was forced to change only after lawsuits mandated improved care and the development of community programs. Medical

care, patient rights, and social justice have since advanced quite substantially in the U.S., no doubt a result of similar parent advocacy and lawsuits.

The deinstitutionalization movement in California began prior to any long-term studies of health outcomes. Only later did studies show increased mortality (SSBA; Strauss, Anderson, Shavelle, Sheridan and Trenkle, 1998; Strauss and Shavelle, 1997; Strauss and Shavelle, 1998; Strauss, Kastner and Shavelle, 1998; Strauss, Shavelle, Anderson and Baumeister, 1998; S&S; Strauss and Kastner, 1996; Strauss, Eyman and Grossman, 1996). By then the movement was in full swing, and — due to large fixed and opportunity costs — the per patient costs in the depleted institutions were even higher.

Deinstitutionalization was one putative way to cut costs, at least temporarily. The current fiscal situation in California, however, is now worse than when deinstitutionalization began in 1993. Services to the DD population have already been cut, and patient co-payments increased. This trend will undoubtedly continue, as the state must find ways to cut costs in order to comply with the entitlements guaranteed by The Lanterman Act.

Cost may be one drawback of institutional care (though the total cost to society of community living is difficult to assess). Another consideration is that children and adults are not integrated into society as a whole. The Lanterman Act grants clients the right to receive services in the least restrictive environment; that is, a place close to the parents' home community where others without disabilities also receive their services. The services here include medical care and, most recently, living accommodations. There is an analogous law governing education of the disabled in the United States. This is "The Education For All Handicapped Children Act", Public Law 94-142. According to PL 94-142 all handicapped children must be provided with educational services in the least restrictive environment; this is called "mainstreaming" as it mandates that the disabled be educated as closely as possible to their non-handicapped peers. But movement from large group care facilities to community care is not always the best choice. Voice of the Retarded, a U.S. organization that advocates for the disabled, is now "fighting to prevent another failed experiment at Fernald [the facility cited above]: namely, the relocation of 275 adult and elderly people with mental retardation who will give up familiar staff, peers and physical environment without the capacity to understand or talk about any of those losses. We believe the risks of these forced relocations far exceed the benefits to our family members" (Voice of the Retarded, 2004).

The results in this and previous studies indicate an increased mortality rate, above that which would be expected. The cost savings of deinstitutionalization and social value of integration must be balanced against this increased risk.

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