

Policy

Research Brief

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Health Status, Health Care Utilization Patterns, and Health Care Outcomes of Persons with Intellectual Disabilities: A Review of the Literature

This Policy Research Brief reviews the current literature in the area of health care needs of people with intellectual and other developmental disabilities and allied medical conditions, looking at the degree to which such individuals are or could be receiving medical care in the community. It provides a summary of research relevant to improving the service delivery system by addressing barriers to community medical care and services, determining what services are needed, and developing strategies and assurances for provision of quality medical care.

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■ Introduction

The U.S. Supreme Court made a landmark decision on June 22, 1999 by ruling in *Olmstead v. L.C.* that under the Americans with Disabilities Act (ADA), institutionalization of a person with a disability who, with proper support, would be able to and would choose to

live in the community is unjustifiable discrimination. This decision opens new opportunities for people with disabilities to live in the community, regardless of the severity of their intellectual disability, mental illness, or medical/health conditions. It also raises questions about the nature and quality of health services available in the community to persons who might otherwise be institutionalized.

The immediate impact of the decision is for people with disabilities who currently live in institutional settings. In 2001, the General Accounting Office (GAO) estimated that at least 1.8 million people with disabilities are being served in institutional settings (GAO, 2001). Of this 1.8 million, 1.6 million individuals live in nursing homes; 106,000 live in institutions for people with intellectual and other developmental disabilities; and 57,000 reside in state and local facilities for individuals with mental illness (GAO, 2001).

The decision also affects people who are living in the community but are at risk of institutionalization. The number of such people is difficult to establish. However, the GAO estimated that nationwide, "...2.3 million adults of all ages lived in home or community-based settings and required considerable help from another person to perform two or more self-care activities" (GAO, 2001, p. 7).

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota.

With the long-standing demands to live in the community coupled with the backing of the *Olmstead* ruling, states are faced with the challenge of providing community services to all persons with disabilities. For people with intellectual disabilities and allied medical and health conditions, the provision of community services could be difficult.

A decade ago we conducted a literature review that analyzed existing research on health needs of people with intellectual disabilities and possible barriers to integration in the community, and found there were barriers to the provision of services to people with intellectual disabilities and allied medical conditions (Hayden & DePaepe, 1991). Some people had unmet medical needs, and the availability of and access to community health services was problematic for others. However, findings also indicated that persons with significant medical conditions are living in community settings, and medical supports can be and are being provided to community members with complex medical needs.

In light of the *Olmstead* decision and the age of the last literature review in the area of health needs of people with intellectual disabilities and allied medical conditions, a literature review was conducted to update the original review. It examined all identifiable literature on health status, utilization patterns of health care, and health care outcomes of persons with intellectual and other developmental disabilities. We believe this update will be useful in informing state and federal policymakers in their future decisions.

■ Method

Research studies and reports for this review were identified by four means. First, a computer search was conducted of the *Psychological Abstracts* and *ERIC* databases from 1989-2001 using appropriate descriptors (e.g., medical conditions, health status, utilization patterns, level of care needs, health-related outcomes, adults, intellectual or developmental disabilities, mental retardation, community, institutions, deinstitutionalization). Second, requests were made to all state developmental disabilities planning councils, University Centers for Excellence in Developmental Disabilities (formally called University Affiliated Programs), and state directors of mental retardation/developmental disabilities programs. Requests were made for any related reports or studies that the agencies may have conducted that addressed the following

topical areas: (a) medical conditions, (b) health status, (c) utilization patterns, (d) level of care needs, and (e) health-related outcomes. In addition, the “ancestry approach” was used to identify other studies from the reference lists of previously identified studies. Finally, a manual review was conducted of all articles published in related journals from 1989-2001.

Eighteen studies and reports met one or more of the criteria. The criteria included the following:

- a. Described the medical conditions, health status, health care access, health care outcomes, utilization patterns, and levels of care needed by groups of individuals with intellectual disabilities and related conditions who lived in institutional and community settings, or who lived in different community settings, or who lived in institutions and were recommended for community placement; and/or
- b. Compared the medical conditions, health status, utilization patterns, level of care needed, and health-related outcomes of persons who moved to the community with their counterparts who lived in institutions and remained at those facilities; and/or
- c. Included types of medical care and services needed to retain persons with intellectual disabilities and medical needs in the community; and/or
- d. Identified barriers that inhibit the provision of community-based medical care and services; and/or
- e. Made recommendations for improving the community medical care and related health services.

■ Results

Overview of Tables

The 18 studies are summarized in Tables 1-3 (see pp 10-17). Four of the 18 studies are cited twice in the tables because they provided information related to people who only lived in the community and to people living in institutions and their counterparts living in the community. Table 1 summarizes four studies related to the health status of individuals with intellectual disabilities who reside in the community. Table 2 summarizes six studies related to the health care outcomes and utilization patterns of people with intellectual disabilities who reside in the community. Table 3 summarizes 10 comparison studies related to health status, health care access, and utilization patterns of people who reside in institutions versus those living in the community.

Community Living: Health Status and Health Care Access

Table 1 (pp 10-11) summarizes four descriptive studies. One study examined the health status of independently living adults and adults living in their parental homes or community residences (Edgerton, Gaston, Kelly, & Ward, 1994). The remaining three studies examined previously institutionalized persons who were living in the community at the time of the study (Brown, 1998; Conroy, Lemanowicz, Feinstein, & Bernotsky, 1991; Conroy, Seiders, & Yuskas, 1998). The level of intellectual disability for the previously institutionalized individuals was either not specified (Brown, 1998), indicated as "mild" (Edgerton et al., 1994), or ranged from "profound" to "mild" (Conroy et al., 1991; Conroy et al., 1998). The following summarizes each study's results:

- **Brown, 1998.** The status of people who were discharged from state-operated congregate housing and care facilities and who moved into new community living arrangements were examined. Over four years, almost half of the respondents saw the overall health of the movers as improved. They also indicated that most respondents saw the quality of medical services as better or unchanged. In addition, they viewed the movers' overall welfare and well-being as better. About 20% said the movers' welfare and well-being had not changed. Moreover, the majority of respondents believed that access to special therapies and medical services had improved since the individuals moved to the community.
- **Conroy, Lemanowicz, Feinstein, & Bernotsky, 1991.** Of the 569 subjects, 72.4% lived in group homes that included four or more individuals. These homes were either Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) (64.1%) or non-ICFs-MR (35.9%). The remaining people lived in either community living arrangements of three or fewer people (22.3%); supervised, supported, or cooperative homes (3.3%); or community training homes (2.0%). Of the total number of subjects, respondents indicated that nearly 2% would not survive without 24-hour medical personnel in 1985 and 3.2% in 1990. In both 1990 and 1995, fewer than 6% had a life-threatening condition that required rapid access to medical care. Of the total number of subjects, 54.8% had no serious medical needs in 1985 and 49.4% had none in 1990. There was a slight increase in the percentage of people needing visiting nurse and/or doctor's visits from 1985 to 1990. The average number of medications received each day increased from 1.6 in 1985 to 1.9 in 1990.
- **Conroy, Seiders, & Yuskas, 1998.** Of the 40 people in supported living settings, respondents indicated that 18% of the subjects had a major health problem, 23% had seizures, 3% had a physical disability, and 3% had a brain injury, yet 90% said their general health was good to excellent. Moreover, 36% of the respondents said their health care was excellent and 30% said health care was very easy to obtain. The median number of doctor visits was eight. Of the 981 individuals living in other community settings, 17% had a major medical problem, 22% had seizures, 17% had cerebral palsy, 15% had a physical disability, and 9% had a brain injury, yet 84% of the respondents rated the subjects' general health as good to excellent. Additionally, 48% rated their health care as excellent and 26% said their health care was very easy to obtain. The median number of doctor visits was 11.
- **Edgerton, Gaston, Kelly, & Ward, 1994.** The people in this study lived independently or in their parental homes. There was considerable diversity in health status and access to health care within each group. Individuals who lived on their own tended to have fewer physical disabilities and ailments than their counterparts. People who lived in residential facilities or with relatives usually had adequate health care provided for them, whereas individuals who lived more independently had difficulty accessing health care. The majority of people living with their families or in congregate care residences had their health care needs monitored by others. Everyone who lived independently needed the assistance of a benefactor to make the initial appointment or to maintain contact with their physician or clinic. Individuals who lived independently had difficulty determining when they needed health care, communicating their needs to care providers, and understanding how to cooperate with the treatment plan. Additionally, they had difficulty locating appropriate care. Few people received thorough physical exams. There was frequent failure of physicians to order pap smears and mammograms for women and to conduct prostate exams for men. The majority of both groups had difficulty understanding medical terminology and few could provide enough information for even a minimally adequate medical history. Most of the older individuals were not sufficiently literate to follow written instructions, and few could remember doctors' instructions well enough to carry them out.

Community Living: Health Care Outcomes and Utilization Patterns

Table 2 (pp 12-13) summarizes six descriptive studies on health care outcomes and utilization patterns among people living in the community. Three studies examined individuals with intellectual disabilities but did not specify the level of intellectual disability (Friedman, Kastner, Pond, & O'Brien, 1989; Noll & Desmond, 1993; South Dakota, 1996). The remaining three studies included people with "mild" to "profound" intellectual disabilities (Conroy, 1995; Like & Spitalnik, 1992; Spitalnik & Like, 1994). Four of the six studies indicated that people lived in the community, but did not specify the type of living arrangements (Friedman et al., 1989; Like & Spitalnik, 1992; South Dakota, 1996; Spitalnik & Like, 1994). Below are summaries of each study:

- **Conroy, 1995.** This study followed 520 class members who moved from a state-operated institution to the community. In 1995, follow-up data were collected for 427 people. These 427 people had a range of additional disabilities. These disabilities included vision (44.3%), physical disabilities (40.7%), hearing (10.8%), cerebral palsy (8.9%), feeding tube (8.7%), autism (6.3%), and tracheotomy (0.5%). In 1990 and 1995, follow-up data were collected for 382 of the 520 class members. Of this number, 60.7% received nursing services in 1990 and 30.6% said they received nursing services in 1995. Additionally, in 1990, less than 2% indicated they had "occasional or frequent problems in receiving medical services," and in 1995, 5.8% reported they had "occasional or frequent problems in receiving medical services."
- **Friedman, Kastner, Pond, & O'Brien, 1989.** Routine health care examinations found 20.3% of the people had previously unrecognized hypothyroidism and 1.2% had previously unrecognized hyperthyroidism. Twenty-six of the 66 individuals were found to have positive antimicrosomal, anti-thyroglobulin and/or antibody test results. There was a higher than expected number of people under 30 years of age with autoimmune hypothyroidism.
- **Like & Spitalnik, 1992.** This descriptive study documented the health services utilization of a group of 80 adults with intellectual disabilities and associated developmental disabilities who had received their primary care at a family practice center in New Brunswick, New Jersey. There were a total of 346 family practice visits made by the 80 participants in the study. Additionally, the study participants had 550 clinical laboratory tests of which 84.7% included blood chemistry tests, hematology tests, automated blood chemistry profiles, urine analyses, and immunology tests. The median number of family practice clinic visits per person was four. People ages 21-44 accounted for 78.6% of the visits. The median number of visits for people ages 21-44 was four and for people ages 45-73 was six. People with mild intellectual disabilities accounted for 35.8% of the visits, those with moderate intellectual disabilities accounted for 36.4% of the visits, and those with severe/profound intellectual disabilities accounted for 24.9% of the visits. The median number of visits for both individuals with mild intellectual disabilities and with moderate intellectual disabilities was four, and for those with severe/profound intellectual disabilities was three.
- **Noll & Desmond, 1993.** This study involved people who lived in a range of congregate, community homes. Of the 256 participants, 97% had a primary care physician, 99.6% saw the physician within the past two years, and 80% saw the physician in a private office. Within the past two years, 61% of the people saw an ophthalmologist, 31% saw a psychiatrist, 27% saw a neurologist, 17% saw an orthopedist, 14% saw a dermatologist, and 4% saw a cardiologist. People rated the quality of their overall medical care between good and excellent. Providers seen in private office settings were rated higher than those seen in a clinic.
- **South Dakota, 1996.** This study examined the status of 75 adults who were discharged from a state-operated facility to the community. Of the 75 adults, no one experienced significant health concerns as a result of moving to the community. The weights of many people fluctuated. For those who lost weight, they remained within their ideal weight range. Three people received gastrostomy tubes. Six months after the move, there had been 18 visits to the emergency room, 15 to the hospital, and 2 to the clinic.
- **Spitalnik & Like, 1994.** Of the 71 participants in the study, there were 371 family practice visits within one year. Of the 550 clinical laboratory tests, 84.7% included blood chemistry tests, hematology tests, automated blood chemistry profiles, urine analyses, and immunology tests. The median number of visits per person was five. People ages 21-44 years old accounted for 81.1% of the visits. The median number of visits for people ages 21-44 was 5 and for people ages 45-73 was 4.5. People with mild intel-

lectual disabilities accounted for 42.9% of the visits, people with moderate intellectual disabilities accounted for 29.1% of the visits, and people with severe/profound intellectual disabilities accounted for 28% of the visits. The median number of visits for individuals with mild intellectual disabilities was four. For their counterparts with moderate intellectual disabilities, the median number of visits was five, and for people with severe/profound intellectual disabilities, the median number of visits was three.

Community Living: Comparison of Health Care Outcomes and Utilization Patterns

Table 3 (pp. 14-17) summarizes studies that compared the health care outcomes and utilization patterns of people who reside in institutions and the community. Four studies compared movers to stayers (Brown & Bretting, 1998; Conroy, Lemanowicz, et al., 1991; Conroy, Seiders, et al., 1995; Conroy, Seiders et al., 1998). Two studies compared the health status, health care access, and utilization patterns of a group of individuals at the time they lived in an institution to one year after they moved to the community (Litzinger, et al., 1993; Tyler & Bourguet, 1997). Three studies compared people who currently lived in an institution to those who lived in some type of community residence (Lakin, Anderson, Hill, Bruininks, & Wright, 1991; Rimmer, Braddock, & Fujiura, 1993; Rimmer, Braddock, & Marks, 1995). One study compared people from the general population to those who lived in an institution, in an Intermediate Care Facility for the Mentally Retarded (ICF/MR), and with their families (Rimmer, Braddock, & Fujiura, 1994). Although all of the studies indicated that participants had an intellectual disability, two did not specify the level of intellectual disability (Brown & Bretting, 1998; Conroy, Lemanowicz et al., 1991). The level of intellectual disability among individuals from the other studies ranged from "borderline/mild" to "profound." Below are the summaries:

- **Brown & Bretting, 1998.** Few individuals reported that they chose their own doctor in either setting. Over time, more community residents saw a doctor they liked. Movers consistently indicated that they saw a doctor when needed. Of the people living in the community, 67-74% reported that their doctor always spent enough time with them. People living in both settings indicated that their doctor always helped them. Staff knowledge about health and

medical needs was rated as excellent or acceptable in both settings, although a greater percentage of post-move staff members exhibited an excellent level of knowledge.

- **Conroy, Lemanowicz, et al., 1991.** Adults living in institutions and in the community indicated that, on the average, they had received a general medical examination within the previous six months. Movers and stayers were equally in need of health care in 1985 and 1990. There were no changes in medical needs over time for either group. There were also no differences between groups in the average numbers of medications received each day.
- **Conroy, Seiders, et al., 1995.** Respondents were asked, "In general, how is this consumer's health?" Responses ranged from 1 (very poor) to 5 (excellent). The average score for people living in the institution was 3.74 and for their counterparts living in the community was 3.86. The average number of illnesses in the past 28 days for both stayers and movers was less than one. The average score for general health status in 1995 was three times higher for stayers than movers. Respondents were also asked to rate the quality of health care on a five-point Likert scale (1 = very poor; 2 = poor, 3 = fair, 4 = good, and 5 = excellent). On the average, people living in institutions rated primary physician services (4.13), nursing services (4.19), services during an acute illness (4.47), emergency care (4.38), and inpatient hospital care (4.19) as "good." On the average, individuals living in the community typically rated primary physician services (4.00), nursing services (4.17), services during an acute illness (3.94), emergency care (3.76), and inpatient hospital care (3.66) as "good" or slightly less than "good." For stayers, the average number of doctor contacts for acute illness was 2.4 in 1994 and 3.2 in 1995, for normal preventive care the average number contacts was 12 in 1994 and 11.5 in 1995, and for specialists the average number was 4.2 in 1994 and 5.2 in 1995. For movers, the average number of doctor contacts for acute illness was 1.3 in 1994 and 1.5 in 1995, for normal preventive care the average number contacts was 5.7 in 1994 and 6.3 in 1995, and for specialists the average number was 5 in 1994 and 5.7 in 1995. The average person living in an institution saw a physician 19.9 times in 1995 and 18.6 times in 1994, compared to 13.5 times in 1995 and 12 times in 1994 for the average individual

living in the community. Further examination of these findings indicated that both groups were roughly similar in the frequency with which they saw specialists and physicians for an emergent illness. Both groups were equally likely to be seen by a specialist. However, people living in the institution had more visits for preventive care than those living in the community. They saw a doctor twice as often as their community counterparts for acute illnesses. The average number of hospital admissions in 1994 and 1995 was less than one for both stayers and movers. The average number of emergency room visits in the previous year was also less than one.

- **Conroy, Seiders et al., 1998.** Nearly 17% of the movers and 34.8% of the stayers had major medical problems: 15.9% of the movers and 12.4% of the stayers had cerebral palsy, 21.2% of the movers and 31.2% of the stayers had seizures, 8.2% of the movers and 12.8% of the stayers had a brain injury, and 13.7% of the movers and 23.3% of the stayers had a physical disability. Respondents were asked to rate the quality of health care on a five-point Likert scale (1 = very poor; 2 = poor, 3 = fair, 4 = good, and 5 = excellent). The average score of general health for stayers was 3.7 and for movers 4.1. The average number days of illness in the previous 30 days for stayers was 1.2 and for movers the average number days was nearly 1. The average score on “how easy it was to find health care” was 3.7 for movers. Over 92% of the movers had a primary physician. The average score for “how good is the health care” for stayers was 4.7 and 4.4 for movers. The average number of doctor visits in the previous year for stayers was 52.4 and 13.5 for movers. The percent of normal care visits in the past years for stayers was 94.6% for stayers and 97.2% for movers; the percent of acute visits was 48.5% for stayers and 21.3% for movers. The percent of stayers and movers who were admitted to a hospital in the previous year was 14.6% and 11.5%, respectively. The average number of hospital admissions in the past year for stayers and movers was less than .50.
- **Lakin, Anderson, et al., 1991.** This study compared health conditions and health service use among a nationally representative sample of 370 individuals 62 years or older in 235 residential settings. Respondents were facility staff or administrators who had known the individual for six months and knew the individual well. Researchers found no facility-related differences in the prevalence of high blood pressure, arthritis, and heart disease. The state institution residents had significantly higher prevalence of neurological disorders, respiratory disorders, back problems, and muscle atrophy/contractures than did individuals living in other types of facilities. In the previous month, 46.1% of the people living in foster care, 52.9% residing in group homes, 67.8% living in large private facilities, and 93.7% residing in state-operated institutions were visited by a nurse. In the previous year, a physician visited 7.1% of the people living in foster care, 7.7% residing in group homes, 9.6% living in large private facilities, and 18.3% residing in state-operated institutions. The number of hospitalizations over the previous year was not significantly different across facilities nor were there significant differences in health-related limitations.
- **Litzinger, et al., 1993.** Investigators from this study compared the health status of a group of adults who lived in an institution to their health status one year out of the institution. They were considered to be “medically fragile” and to have “complicated seizure disorders.” Most were on multiple medications, and a few took barbiturates. The simplification of anti-convulsants, early intervention for seizures, and improved staff education resulted in fewer seizures, a decrease in emergency room visits, and an increased level of functioning.
- **Rimmer, Braddock, & Fujiura, 1993.** Of the 364 people in this study, 27.5% of the men and 58.5% of the women were obese. When the type of living arrangement was compared, researchers found that 16.5% of the people living in the institutions, 50% of those living in ICFs/MR, 40.9% of the individuals living in group homes, and 55.3% of persons living with their family were obese. When level of intellectual disability was compared, 46.5% of the people with mild retardation, 53.2% of those with moderate retardation, and 29.4% of those with severe/profound retardation were obese.
- **Rimmer, Braddock, & Fujiura, 1994.** Researchers found that adults with mild to severe intellectual disabilities had cardiovascular risk profiles similar to those without intellectual disabilities. However, people living in group homes and natural family settings tended to have higher “at risk” rates, depending on the risk factor and gender.

- **Rimmer, Braddock, & Marks, 1995.** People living in institutions had lower body weights, lower body mass indexes (BMIs), lower percent body fat levels, lower total cholesterol and low-density lipoprotein cholesterol (LDL-C) levels, lower triglycerides (TG), and a lower ratio of total cholesterol to high-density lipoprotein cholesterol (HDL-C) than their counterparts living in group homes and natural family settings. Although the overall use was low across all groups, people living in group homes smoked more, drank more alcohol and coffee, and exercised less than those living in institutions and with their families.
- **Tyler & Bourguet, 1997.** In the first year following a move from an institution to a group home, each person averaged 6.6 office visits to a family physician. Once in the community, physicians identified newly major health problems (e.g., chronic persistent hepatitis due to hepatitis B, dysphagia, acid peptic disease, gastroesophageal reflux disease, absence seizures, primary degenerative dementia, bronchiectasis, and idiopathic iridocyclitis). Additionally, significant changes in pharmacotherapy occurred. For example, anti-convulsants were initially prescribed for five people: two received triple-drug therapy, two received two-drug therapy, and one received one-drug therapy. One year later, with no worsening of seizure control, no one required triple-drug therapy, two people received two-drug therapy, and three individuals received one-drug therapy. Moreover, health maintenance practices included hepatitis B immunization, cholesterol determinations, smoking cessation counseling, and calcium supplementation.

■ Discussion

Several methodological limitations among the studies limit the conclusions about health status, utilization patterns, and health care outcomes. The majority of the studies did not utilize matched comparison or control groups; rather, several studies conducted either medically related pre-post-measures or followed subjects over a period of time. In addition, group formation and subject selection also varied across studies. Representativeness of the subject samples studied and criteria for inclusion in the samples were variable, since groups typically constituted naturally

assembled collectives. Moreover, a variety of instruments and informants were utilized to obtain medical information, which made comparison across studies difficult. Finally, several researchers utilized interviews or questionnaires that they developed for their particular study, and it is unknown whether these instruments were tested for psychometric soundness.

The studies contained within the literature review were descriptive and comparative in nature. These types of studies allow the reader a brief look at the lives of individuals at one point in time. However, they do not allow identification of factors that influence health-related outcomes, nor an examination of what factors operate in combination with one another as broader factors or as multiple predictors in discriminating among groups or persons with different living experiences.

Overall, the descriptive studies indicated that the health of people with intellectual disabilities who moved from an institutional setting to the community improved. Additionally, medical services received were rated as being either better or unchanged and access to services improved. One study noted that previously undiagnosed medical conditions were identified in the community. However, one study found that people living in community residences or with relatives had adequate health care and access to medical services where their counterparts who lived on their own had difficulty obtaining and accessing services (Edgerton et al., 1994).

The findings from the comparative studies were consistent with those from the descriptive studies. The overall health of institutionalized people and their counterparts who lived in the community was unchanged or improved after leaving institutions. Access to services was considered timely and appropriate. Medical services received were rated as being either better or unchanged. Moreover, as people obtained more personal independence they tended to have higher "at risk" rates for cardiovascular profiles and for unhealthy lifestyles.

Consistent with the previous literature review (Hayden & DePaepe, 1991), persons who resided in state institutions utilized health services and professionals more frequently than those who lived in the community. Whether this is the result of the medical conditions of persons who reside in institutions requiring more frequent medical care and monitoring than those of persons who live in the community, or whether people see health professionals more often

because the health professionals work on site, remains unclear. Researchers have suggested that the higher medical service use by people in institutions may be related to either “administrative procedures” (Silverman, Silver, Lubin, Zigman, Janicki, & Jacobson, 1984) or the organizational differences within the service delivery models unutilized in those facilities (Lakin et al., 1991). However, a conclusive determination of the precise factors that are responsible for this higher service use has not been made at this time.

The findings from this literature review are consistent with those of the previous one conducted by Hayden and DePaepe (1991). Findings reflect the fact that the outcome data reported across studies was general and variable; as a result, it was difficult to draw direct conclusions from these noncomparable measures. Yet there is evidence to indicate that (a) there are individuals with varying degrees of intellectual disability and medical care needs living in the community, (b) people with significant medical conditions can be placed and maintained in more normalized community settings, and (c) medical supports can be and are being provided to people with intellectual disabilities and allied medical conditions to enable them to live in the community. However, some people had unmet medical needs, and the availability of and access to community-based services was problematic for others. These contradictory findings indicate that it is possible to serve people with intellectual disabilities who have medical problems in the community, but the service delivery system has room to make improvements. Until improvements are made within the medical service delivery system, it is important for advocates to acknowledge there are barriers to the provision of medical care and services, to address the barriers to the provision of community medical care and services, to determine what services are needed, and to develop strategies and assurances that quality medical care is available in the community.

The task for human service administrators and advocates in light of the *Olmstead* decision is to plan, coordinate, and monitor comprehensive medical services to individuals with intellectual disabilities, regardless of where they live. In relation to the community medical service system, advocates, particularly those with disabilities, health providers, service administrators, and researchers need to work together to examine (a) the relationship between the type of community living setting and the quality of health care received and access to health care, (b) how to improve health professionals’ abilities to explain medical terminology to people with

intellectual disabilities, (c) how to provide a medical history to people with intellectual disabilities that they can share with their doctors, and (d) methods that will help people with intellectual disabilities to understand written instructions and recall doctors’ instructions. Second, professionals need to evaluate the person’s medical needs and to develop a comprehensive plan that will meet the individual’s needs in the community. Third, states need to coordinate services within and across agencies and professionals for cost-containment purposes and to increase the dissemination of information. Fourth, state mental retardation/developmental disabilities agencies need to develop a monitoring system to assess the quality of medical services provided and to identify any unmet medical service needs. Fifth, medical personnel need to be provided with more incentives to participate in the Medicaid program.

In conclusion, findings are consistent with the statement made by Crocker in 1991:

Our ability in current times to provide accurate health care for adults with mental retardation is improved but incomplete. Taken as a class, these persons are obviously of diverse personal and clinical background, and generalizations should be approached cautiously. For the majority, the medical needs can be expected to approximate those of average persons, although influences may occur because of altered personal independence and self-care practices and from particular past experiences and supports. Others have special vulnerabilities deserving preventive and therapeutic assistance (p. 165).

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Table 1: Descriptive Studies: Health Status and Health Care Access of Individuals with Intellectual Disabilities Who Reside in the Community

| Author (date) | State | Year of Data Collection | Number of Subjects | Age (in years) | Level of Retardation (percentage) | Type of Setting (n) | Health Status/Health Care Access |
|-----------------------------------|-------|-------------------------|--|------------------|--|---|--|
| Brown (1998) | NM | 1994-1997 | Year 1 = 31 Year 2 = 33 Year 3 = 39 Year 4 = 42 | Adults X = 40 | Not specified | Community | <ul style="list-style-type: none"> • Over 4 years, almost half of the respondents saw the overall health of the movers as improved. • Over 4 years, most respondents saw the quality of medical services as better or unchanged. • Most respondents viewed the movers' overall welfare and well-being as better. About one-fifth said it had not changed. • The majority of the respondents believed that access to special therapies and medical services had improved since the individual moved to the community. |
| Conroy, Lemanowicz, et al. (1991) | CT | 1985 1990 | 569 ¹ | 22-93 | Mild (11.0) Moderate (16.0) Severe (29.0) Profound (44.0) | Group Home ² (412) Community Living Arrangement ⁶ (127) Supervised/Supportive Living (19) Community Training Home (11) | <ul style="list-style-type: none"> • 54.8% had no serious medical needs in 1985; 49.4% had none in 1990. • 1.9% would not survive without 24-hour medical personnel in 1985; 3.2% would not in 1990. • 5.3% had a life-threatening condition that required rapid access to medical care in 1985; 5.7% did in 1990. • 36.4% needed visiting nurse and/or doctor's visits in 1985; 41.7% did in 1990. • Average number of medications received each day increased from 1.6 in 1985 to 1.9 in 1990. |
| Conroy, Seiders, et al. (1998) | CA | 1997 | 1,021 | Adults | Supported Living Mild 46.0 Moderate 21.0 Severe 23.0 Profound 10.0 | Supported Living (40) Other Community Settings (981) | <ul style="list-style-type: none"> • Of the 40 people in supported living settings, 90% said their general health was good to excellent. 18% had a major health problem, 23% had seizures, 3% had a physical disability, and 3% had a brain injury. 36% said their health care was excellent and 30% said their health care was very easy to obtain. The median number of doctor visits was 8. • Of the 981 individuals living in other community settings, 84% rated their general health as good to excellent. 17% had a major medical problem, 22% had seizures, 17% had cerebral palsy, 15% had a physical disability, and 9% had a brain injury. 48% rated their health care as excellent and 26% said their health care was very easy to receive. The median number of doctor visits was 11. |

| Edgerton, et al. (1994) | National | Unknown ⁴ | 47 | 63+ | Mild | Independent (17) Parental Homes or Community Residences (30) | <ul style="list-style-type: none"> • There was considerable diversity in health status and health care within each group. Individuals who lived on their own tended to have fewer physical disabilities and ailments than their counterparts. • The majority of people living with their families or in congregate care residences had their health-care needs monitored by others. • Everyone who lived independently needed the assistance of a benefactor to make the initial appointment or to maintain contact with their physician or clinic. • Individuals who lived independently had difficulty determining when they needed health care, communicating their needs to care providers, and understanding how to cooperate with their treatment plan. Additionally, they had difficulty in locating appropriate care. • Few people received thorough physical exams. There was frequent failure of physicians to order pap smears and mammograms for women and to conduct prostate exams for men. • The majority of both groups had difficulties in understanding medical terminology and few could provide enough information for even a minimally adequate medical history. • Most of the older individuals were not sufficiently literate to follow written instructions, and few could remember doctors' instructions well enough to carry them out. • People who lived in residential facilities or with relatives usually had adequate health care provided for them, whereas individuals who lived more independently had difficulty accessing health care. |
|-------------------------|----------|----------------------|----|-----|------|--|--|
|-------------------------|----------|----------------------|----|-----|------|--|--|

¹ People moved from an institution in 1985 and lived in the community in 1990.

² Residences with four or more people.

³ Residences with three or fewer people.

⁴ Two samples were examined and contrasted over a period of five years.

Table 2: Descriptive Studies: Health Care Outcomes and Utilization Patterns of Persons with Intellectual Disabilities Who Reside in the Community

| Author (date) | State | Year of Data Collection | Number of Subjects | Age in years (percentage) | Level of Retardation (percentage) | Type of Setting (n) | Health Care Outcomes and Utilization Patterns |
|-------------------------|-------|-------------------------|--------------------|---|--|--|---|
| Conroy (1995) | OK | 1995 | 427 | 0-20 (6.8) 21-30 (51.1) 31-40 (41.9) 41+ (0.2) | None (.5) Mild (12.9) Moderate (11.5) Severe (19.2) Profound (48.7) Unknown (7.3) | Independent/supported living (355) Adult companion (23) Natural family home (22) Group home ¹ (17) Other (10) | <ul style="list-style-type: none"> • Of 425 people, 28% received nursing services. • Of 382 people, 5.8% reported that they had occasional or frequent problems in receiving medical services. |
| Friedman, et al. (1989) | NJ | Unknown | 138 | 2-59 | Not specified | Community | <ul style="list-style-type: none"> • Routine health care services exams found 20.3% of the people to have previously unrecognized hypothyroidism and 1.2% to have previously unrecognized hyperthyroidism. • 26 of 66 individuals were found to have positive anti-microsomal, anti-thyroglobulin, and/or antibody test results. • Higher than expected number of patients with autoimmune hypothyroidism were under age 30. |
| Like & Spitalnik (1992) | NJ | 10/98-12/90 | 80 | 21-44 (83.8) 45-73 (16.3) | Mild (34.2) Moderate (36.7) Severe/Profound (29.1) | Community | <ul style="list-style-type: none"> • 346 family practice visits were made by all subjects within one year. Median number of visits per person was 4. • 84.7% of clinical laboratory tests (n=550) included blood chemistry tests, hematology tests, automated blood chemistry profiles, urinalyses, and immunology tests. • Median number of visits for people age 21-44 was 4 and for people age 45-73 was 6. • Persons age 21-44 accounted for 78.6% of the visits. • People with mild mental retardation accounted for 35.8% of the visits, those with moderate mental retardation accounted for 36.4% of the visits, and individuals with severe/profound mental retardation accounted for 24.9% of the visits. • Median number of visits for persons with mild mental retardation was 4, those with moderate mental retardation was 4, and people with severe/profound mental retardation was 3. |

| | | | | | | | |
|-------------------------|----|-------------|-----|------------------------------|--|--|---|
| Noll & Desmond (1993) | CT | 1993 | 256 | Not reported | Not specified | Community training homes Community living arrangements ² Campus facilities ³ | <ul style="list-style-type: none"> • 97% have a primary care physician. • 99.6% saw a physician within the past 2 years. • 80% saw physician in private office. • People saw the following specialists within the past 2 years: ophthalmologist (61%); psychiatrist (31%); neurologist (27%); orthopedist (17%); dermatologist (14%); and cardiologist (4%). • People rated the quality of their overall medical care between good and excellent. • Providers seen in office settings were rated higher than those seen in clinic settings. |
| South Dakota (1996) | SD | 3/96-12/96 | 75 | Adults | Not specified | Community ⁴ | <ul style="list-style-type: none"> • Did not experience significant health concerns as a result of moving to the community. • The weights of many people fluctuated. • Those who lost weight remained within their ideal weight range. • Three people received gastroscopy tubes. • 18 visits to the emergency room, 15 hospital visits that lasted a total of 53 days, and 2 visits to clinic for broken toe and broken leg. |
| Spitalnik & Like (1994) | NJ | 10/98-12/00 | 71 | 21-44 (80.3) 45-73 (19.7) | Mild (38.6) Moderate (31.4) Severe/Profound (30.0) | Community | <ul style="list-style-type: none"> • 371 family practice visits were made by all subjects within 1 year. • Persons age 21-44 accounted for 81.1% of the visits. • People with mild retardation accounted for 42.9% of the visits, with moderate mental retardation accounting for 29.1% of the visits, and with severe/profound mental retardation accounting for 28% of the visits. • Median number of visits per persons was 5. • Median number of visits for people age 21-44 was 5 and for people age 45-73 was 4.5. • Median number of visits for persons with mild mental retardation was 4, with moderate mental retardation was 5, and with severe/profound mental retardation was 3. • 82.5% of clinical laboratory tests (n=550) included blood chemistry tests, hematology tests, automated blood chemistry profiles, urinalyses, and immunology tests. |

¹ Group home includes residence of 4 to 6 people (n=5) or 7 or more people, private Intermediate Care Facility for the Mentally Retarded (ICF/MR), and foster home.

² Community living arrangements include community, supportive living, and independent living arrangements.

³ Did not define. They are not long-term care or mental health facilities, residential schools, or Southbury Training Schools.

⁴ Residents moved from a public institution to community homes.

Table 3: Comparison Studies: Health Care Outcomes and Utilization Patterns of People who Reside in Institutions and the Community

| Author (date) | State | Year of Data Collection | Number of Subjects | Age (in years) | Level of Retardation (percentage) | Type of Setting (n) | Health Status, Health Care Access, and Utilization Patterns |
|-----------------------------------|-------|-------------------------|-----------------------------|---------------------------|--|--|---|
| Brown & Bretting (1998) | NM | 1993-1997 | 135 | 11-60 | Not specified | Institution (60) Community 1 year (90) 2 years (96) 3 years (93) 4 years (84) 5 years (36) | <ul style="list-style-type: none"> Few individuals reported they chose their own doctor in either setting. More community residents over time saw a doctor they liked. Movers consistently indicated that they saw a doctor when needed. 67% to 74% of the people living in the community indicated that their doctor always spent enough time with them. People living in both settings indicated that their doctor always helped them. Staff knowledge about the health and medical needs was rated as excellent or acceptable in both settings. A greater percentage of post-move staff members exhibit an excellent level of knowledge. |
| Conroy, Lemanowicz, et al. (1991) | CT | 1985, 1990 | Movers: 124 Stayers: 124 | Adults | Not specified | Institution Community | <ul style="list-style-type: none"> On the average, both groups received a general medical exam within the previous six months. Movers and stayers were equally in need of health care in 1985 and 1990. No changes in medical needs over time, for either group. No differences between groups in the average number of medications received each day. |
| Conroy, Seiders, et al. (1995) | NY | 1994, 1995 | Movers: 745 Stayers: 255 | Movers: 53.5 ¹ | Mild Moderate Severe Profound | Movers 10.0 19.0 35.0 35.0 Stayers 23.0 10.0 12.0 55.0 | <ul style="list-style-type: none"> The average number of days in the past 28 days in which activities were restricted due to illness was 1.18 for people living in the community and 0.73 for those who remained in the institution. The average score for general health status in 1995 was 3.86 for stayers and .83 for movers³. In 1995, the average person living in an institution saw a physician 19.9 times in the past year compared to 13.5 times for the average individual living in the community. For stayers, the average number of doctor contacts for acute illness was 2.4 in 1994 and 3.2 in 1995, for normal preventive care was 12 in 1994 and 11.5 in 1995, and for specialists was 4.2 in 1994, and 5.2 in 1995. |

- For movers, the average number of doctor contacts for acute illnesses was 1.3 in 1994 and 1.5 in 1995, for normal preventive care was 5.7 in 1994 and 6.3 in 1995, and for specialists was 5 in 1994 and 5.7 in 1995.
- For stayers, the average number of hospital admissions in the previous year was .4 in 1994 and .6 in 1995. For movers, the average number was .5 in 1994 and .7 in 1995.
- For stayers, the average number of emergency room visits in the previous year was .4 in 1994 and .9 in 1995. For movers, the average number was .7 in 1994 and 1.1 in 1995.
- 16.8% of the movers and 34.8% of the stayers had major medical problems.
- 15.9% of the movers and 12.4% of the stayers had cerebral palsy. 21.2% of the movers and 31.2 of the stayers had seizures. 8.2% of the movers and 12.8% of the stayers had a brain injury. 13.7% of the movers and 23.3% of the stayers had a physical disability.
- 16.8% of the movers and 34.8% of the stayers had major medical problems.
- 15.9% of the movers and 12.4% of the stayers had cerebral palsy. 21.2% of the movers and 31.2 of the stayers had seizures. 8.2% of the movers and 12.8% of the stayers had a brain injury. 13.7% of the movers and 23.3% of the stayers had a physical disability.
- Average score of general health: stayers 3.7 and movers 4.1.
- Average days of illness in past 30 days: stayers 1.2 and movers 0.9.
- The average score on how easy it was for movers to find health care was 3.7. Average score for how good is health care, stayers 4.7 and movers 4.4.
- 92.4% of the movers had a primary physician. Average total doctor visits in past year, stayers 52.4 and movers 13.5.
- Percent normal care visits in past year: stayers 94.6%, movers 97.2%. Percent acute visits in past year: stayers 48.5%, movers 21.3%.
- Percent hospital admissions in past year, stayers 14.6% and movers 11.5%.
- Average number of hospital admission in past year, stayers 0.23 and movers 0.19.

| Author | Year | State | Movers | Stayers | Institution |
|--------------------------------|------|-------|---------------|---------------|------------------------------|
| Conroy, Seiders, et al. (1998) | 1997 | CA | Mild | 18.1 | Community homes ³ |
| | | | Moderate | 8.5 | Supported living |
| | | | Severe | 13.4 | Independent living |
| | | | Profound | 58.0 | Parent's/Relative's home |
| | | | Movers: 38.6 | Stayers: 8.4 | |
| | | | Movers: 48.5 | Stayers: 7.1 | |
| | | | Movers: 1,073 | Stayers: 14.0 | |
| | | | Stayers: 839 | Stayers: 68.4 | |

Table 3 continued on pp. 16-17.

Table 3: Comparison Studies: Health Care Outcomes and Utilization Patterns of People who Reside in Institutions and the Community (continued)

| Author (date) | State | Year of Data Collection | Number of Subjects | Age (in years) | Level of Retardation (percentage) | Type of Setting (n) | Health Status, Health Care Access, and Utilization Patterns |
|-----------------------------------|----------|-------------------------|--------------------|----------------|---|---|---|
| Lakin, Anderson, et al. (1991) | National | 1982 | 370 | 69+ | Borderline/Mild (25.9) Moderate (25.1) Severe (24.6) Profound (24.4) | Foster care (96) Group home (135) Large private facility (91) State institution (48) | <ul style="list-style-type: none"> • There were no facility-related differences in the prevalence of three most commonly occurring health conditions: high blood pressure, arthritis, and heart disease. • State institution residents had significantly higher prevalence than did people from other types of facilities for neurological disorders, respiratory disorders, back problems, and muscle atrophy/contractures. • Visited by nurse in the past month: 46.1%-foster care, 52.9%-group home, 67.8%-large private facility, and 93.7%-state institution. • Physician visits in the past 12 months: 7.1%-foster care, 7.7%-group home, 9.6%-large private facility, and 18.3%-state institution. • The number of hospitalizations over the previous year were not significantly different across facilities nor were there significant differences in health-related limitations. |
| Litzinger, et al. (1993) | UT | 1988-1990 | 15 | 22-40 | Profound to Severe | Institution Community | <ul style="list-style-type: none"> • Compared status in institution to one year out of the institution. • People were considered to be "medically fragile" who had "complicated seizure disorders." Most were on multiple medications, and few took barbiturates. • Simplification of anti-convulsants, early intervention for seizures, and improved staff education resulted in (a) fewer seizures, (b) a decrease in emergency room visits for status seizures and drug-related side effects, and (c) an increased level of functioning as measured by activities of daily living. |
| Rimmer, Braddock & Fujiura (1993) | IL | Unknown | 364 | 17-72 | Mild ^d Moderate ^e Severe/Profound ^f | Institution (103) ICF/MR ^s (94) Group home ^e (44) Natural family (123) | <ul style="list-style-type: none"> • 27.5% of the men and 58.5% of the women were obese. • 16.5% of the people living in institutions, 50% of those living in ICFs/MR, 40.9% of those living in group homes, and 55.3% of those living with their families were obese. • 46.5% of people with mild retardation, 53.2% of those with moderate retardation, and 29.4% of those with severe/profound retardation were obese. |

| | | | | | | | |
|-----------------------------------|----|-----------|-----------------|-------|---|--|--|
| Rimmer, Braddock & Fujjura (1994) | IL | Unknown | 329 | 17-70 | Mild to severe | <p>Large facilities⁷ (184) Group home⁵ (106) Natural family (184) General population⁷</p> | <ul style="list-style-type: none"> Adults with mental retardation had cardiovascular risk profiles similar to those without mental retardation. The group home and natural family settings tended to include higher "at risk" rates, depending on the risk factor and gender. |
| Rimmer, Braddock & Marks (1995) | IL | Unknown | 329 | 17-70 | Mild to severe | <p>Large facilities (184) Group home (106) Natural family (184)</p> | <ul style="list-style-type: none"> People living in institutions had lower body weights than their counterparts who lived in group and family homes. They also had lower total cholesterol and low-density lipoprotein cholesterol to high-density lipoprotein levels than their counterparts. Persons living in institutions had lower body mass index and percent body fat levels compared to those living with their families. They also had lower triglycerides and ratio of total cholesterol than those living with their families. Although overall use was low, people living in group homes smoked more, drank more alcohol and coffee, and exercised less than those living in institutions and with their families. |
| Tyler & Bourquet (1997) | OH | 1987-1990 | 21 ⁸ | 21-67 | Mild (4.8) Moderate (14.3) Severe (42.8) Profound (38.1) | <p>Group homes Institution Group Homes</p> | <ul style="list-style-type: none"> In the first year following move from institution to group homes, each person averaged 6.6 office visits to a family physician. Newly identified major health problems included: chronic persistent hepatitis due to hepatitis B, acid peptic disease, gastroesophageal reflux disease, dysphagia, primary degenerative dementia, absence seizures, bronchiectasis, and idiopathic iridocyclitis. Significant changes in pharmacotherapy included consolidation of multi-drug anticonvulsant regimens and discontinuance of psychotropics and laxatives. Health maintenance practices included hepatitis B immunization, cholesterol determinations, smoking cessation counseling, and calcium supplementation. |

¹ Average

² Community residences, family care homes, individualized residential alternative homes, ICFs/MR.

³ Range of responses were from 1 (very poor) to 5 (excellent)

⁴ Residences include 15 or fewer people, which include ICFs-MR, Community Care facilities, and foster homes.

⁵ No further information provided.

⁶ Privately operated facility with 16 to 99 residents.

⁷ Privately operated home with 15 or fewer people.

⁸ 16 or more residents.

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