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ABSTRACT

The review summarizes research (1978-1989) on the medical needs of persons with mental retardation living in institutional and community settings. Specifically it addresses six questions: (1) do mentally retarded persons in institutions have more serious medical needs than their community counterparts? (2) when people with mental retardation are moved into the community, does their health/medical status deteriorate? (3) does the community service system provide access to the medical care, resources, and support services needed by the current institutional population? (4) what medical care and services are needed by retarded persons currently in or potentially in the community? (5) what are the barriers to provision of community medical services? (6) what can be done to improve community medical care and services for persons with mental retardation? Among conclusions are that prevalence of different medical conditions is comparable for community residents or institutionalized persons; that persons in state institutions utilize service professionals more frequently than do individuals in the community; that people with mental retardation in the community appear, in general, to be receiving adequate medical and health services; and that the availability of medical care and support services in the community can prevent institutionalization. A table compares the studies reviewed. Includes about 50 references. (DB)

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Living in the Community: Persons with Mental Retardation and Allied Medical Conditions

The deinstitutionalization movement has led to major changes in the nature and focus of the residential service delivery system for people with mental retardation and related conditions. Research indicates two trends: 1) a decrease in the number of people who reside in large institutions, and 2) an increase in the number of persons who live in small, community-based facilities *(White, Lakin, Wright, Hill, & Menke, 1989)*. As states continue to depopulate their large public institutions, they are faced with the challenge of providing community services to persons who have severe cognitive impairments as well as allied medical conditions.

Advocates of maintaining institutional settings contend that among these populations there are significant numbers of individuals who require the 24-hour support and care that can be best provided in institutions. This opposition to deinstitutionalization raises several questions:

- Do persons who currently reside in mental retardation institutions have more serious medical needs than their counterparts who live in the community?
- When people with mental retardation and related conditions are moved into the community, does their health/medical status deteriorate?
- Does the community service system provide access to the type and range of medical care, resources, and support services needed by the current institutional population?

Many strong advocates of deinstitutionalization raise relevent questions that reflect their perspective:

- What medical care and services are needed to meet the health care needs of persons with mental retardation and medical conditions who are already in the community and/or who could move into the community?
- What are the barriers to the provision of community medical care and services to persons who currently live in the community and/or could move into the community?
- What can be done to improve community medical care and services for persons with mental retardation and related conditions?

This brief seeks to address these six questions by summarizing available research on medical needs of persons with mental retardation living in institutional and community settings, the medical services available in both types of settings, and the resources and changes needed to provide quality medical care in community settings to persons with mental retardation and allied medical conditions.

Research Selected for Review

Relevant research for this review was initially identified by four basic means. First, a computer search was conducted of the Psychological Abstracts and ERIC databases from 1978 to 1989 using appropriate descriptors. Second, requests were made to all State Planning Councils, University Affiliated Programs, and state directors of mental retardation programs for any related reports or studies that the agencies may have generated that addressed the six questions. In addition, the "ancestry approach" was used to

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identify other studies from the reference lists of previously identified studies. Finally, a manual review was conducted of all articles published in 27 journals from 1978 to 1989.

Over 60 studies and reports were identified and screened. Of those, 46 met the criteria for inclusion in this review by fulfilling one or more of the following:

- Described the medical conditions, levels of care needed, and health related outcomes of groups of individuals who lived in institutional and/or community settings.
- Compared the medical conditions, levels of care needed, and health related outcomes of persons who lived in institutions to those characteristics for their counterparts who had been moved to the community.
- Identified types of medical care and services needed to retain persons with mental retardation and medical needs in the community.
- Identified barriers that inhibit the provision of community-based medical care and services.
- Provided recommendations for improving the community medical care and related health services.

Key Findings: Overview

The available research does not clearly support one type of residential setting as superior to the others from a health and health care perspective. It also does not support the view that populations within the same general types of settings are homogeneous in terms of health needs and conditions. The studies reveal that there are persons with varying degrees of needs for medical care -- from routine to 24-hour -- living in the community and also in institutions, that there are persons who are experiencing good health in both types of settings, and that there are people having difficulty with their health in both types of settings.

The research provides clearer answers to the questions about the medical care and services needed to maintain persons with mental retardation and related health conditions in the community, and about removal of barriers to provision of those services. It identifies a number of specific characteristics of medical service systems that can enhance or hinder the community living of persons with mental retardation and medical problems.

The major findings of the research review in relation to the six questions raised in this brief are as follows:

■ Question #1: Do persons who currently reside in mental retardation institutions have more serious medical needs than their counterparts who live in the community?

Yes. The majority of the studies found that persons living in an institutional setting had more severe disabilities and more medical problems than their counterparts who moved to the community. However, two studies found individuals who resided in the community were fairly comparable to their peers who lived in an institutional setting. In addition, there was only a small number of individuals who lived in both institutions and community facilities who needed rapid access to medical care or 24-hour medical care.

■ Question #2: When people with mental retardation and related conditions are moved into the community, does their health/medical status deteriorate?

No. The majority of studies noted positive health related outcomes of individuals who were deinstitutionalized. In fact, one study found that many previously unrecognized medical conditions that were present while individuals lived in institutions were identified when they moved into the community. Other studies found positive health related outcomes for residents of both community and institutional settings.

■ Question #3: Does the community service system provide access to the types and range of medical care, resources, and support services needed by the current institutional population?

The findings did not directly answer this question. However, there are people who currently live in the community who have the same type of medical conditions as those who reside in institutions and who have rapid access to medical care or 24-hour medical care. These findings suggest that it is possible for the community to serve people with significant health problems who currently live in institutions.

■ Question #4: What medical care and services are needed to meet the health care needs of persons with mental retardation and medical conditions who are already in the community and/or those who could move into the community?

Various studies suggested a need for an accessible organized system of primary care available in the immediate community; ongoing primary and specialty physicians to provide continuity of care and medical management; effective case management; interagency service coordination; home health care and services; accessible medical supports, such as on-call and 24-hour nursing; additional trained direct care staff; and transitional group homes for short term medical care and stabilization.

Question #5: What are the barriers to provision of community medical care and services to persons who currently live in the community and/or could move into the community?

Studies identified four categories of barriers: disincentives toward support of this population in community residences; problems related to the funding and payment of medical care and services; inadequate training and knowledge on the part of physicians about persons with mental retardation, and a lack of health care information shared with direct care providers caring for persons with more complex medical needs; and geographic barriers in the form of inaccessible or unavailable medical care and services due to location.

Question #6: What can be done to improve community medical care and services for persons with mental retardation and related conditions?

The majority of studies recommended additional training and education for medical personnel and direct care providers. Other studies cited the need for certain additional medical services, supports, and resources. In addition, others suggested either improved interprofession and interagency coordination, or ongoing monitoring of medical needs and health conditions by health professionals.

Key Findings: In-Depth

In this section, the research findings will be discussed in greater detail. Further information on specific studies can be found in Table 1 and Table 2 on pages 8-21. Table 1 lists descriptive studies and Table 2 lists the comparative studies. The key findings in this section are presented under the following categories:

- **Populations Studied**
- **Medical Conditions**
- **Levels of Care Needed**
- **Health Related Outcomes**
- **Medical Care and Services Needed to Maintain Persons in the Community**
- **Barriers to the Provision of Community Medical Care and Services**
- **Recommendations for Improving Community Medical Care and Services**

Populations Studied

The different population samples examined in the descriptive and comparative studies reviewed were identified as follows:

- Subjects lived in institutions or the community, but were described as one group *(Brown, 1989; Conroy, Feinstein, & Lemanowicz, 1988; Ziring, 1987).*
- All of the residents lived in institutions, but were recommended for community placement *(Minihan, 1986; Vitello, Atthowe, & Cadwell, 1983).*
- Subjects lived in a specific type of community residence *(McDonald, 1985; Springer, 1987).*
- Residents lived in several community settings, but were described as one group *(Feinstein, Lemanowicz, Spreat, & Conroy, 1986; Gollay, Freedman, Wyngaarden, & Kurtz, 1978)*, or as several separate groups *(Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989)*
- Subjects moved to the community and were compared to their counterparts who remained in institutions *(Bradley, Conroy, Covert, & Feinstein, 1986; Conroy & Bradley, 1985; Landesman-Dwyer & Sulzbacher, 1981; Mallory & Herrick, 1987; Seltzer & Krauss, 1984).*
- People who lived in an institutional setting were compared to those who lived in the community *(Brown, 1989; Eyman, Borthwick-Duffy, Call, & White, 1988; Hill & Bruininks, 1981; Jacobson & Janicki, 1985; Jacobson & Schwartz, 1983; Krauss & Seltzer, 1986; Lakin, Anderson, Hill, Bruininks, & Wright, in press; Schor, Smalky, & Neff, 1981; Silverman, Silver, Lubin, Zigman, Janicki, & Jacobson, 1987).*

In addition to identifying subjects according to the types of settings they lived in at the time of the studies, a few reports classified subjects according to previous residential backgrounds. Seven studies were of individuals who lived in community or institutional settings, with "some" of the community residents deinstitutionalized *(Bradley et al., 1986; Conroy & Bradley, 1985; Landesman-Dwyer & Sulzbacher, 1981; Mallory & Herrick, 1987; Schor et al., 1981; Seltzer & Krauss, 1984; Ziring, 1987).* In four other studies, all of the subjects lived in the community and all were deinstitutionalized *(Feinstein et al., 1986; Gollay et al., 1978; McDonald, 1985; Springer, 1987).*

Medical Conditions

The majority of studies found that persons living in an institutional setting had more severe disabilities *(Jacobson & Schwartz, 1983)* and had more medical problems

(Eyman et al., 1988; Mallory & Herrick, 1987; Seltzer & Krauss, 1984) than their counterparts who moved to the community. The medical problems that were most numerous included seizures *(Bradley et al., 1986; Brown, 1989; Hill & Bruininks, 1981; Jacobson & Schwartz, 1983)*, gastro-intestinal illnesses *(Brown, 1989)*, muscle atrophy/contractures, respiratory problems, and back problems *(Lakin et al., in press)*. However, two studies found more medical problems, such as seizures *(Schor et al., 1981)* and musculoskeletal conditions *(Jacobson & Janicki, 1985)*, among people in community residences than among their peers in institutions.

The percentages of residents who had one or more chronic medical conditions varied across studies. For example, 99% of clients in an institution who were waiting for community placement had at least one chronic medical condition *(Minhan, 1986)*, while approximately 68% to 79% of community residents had no serious medical problems *(Bradley et al., 1986; Feinstein et al., 1986)*. Yet, approximately 30% of all residents in a national sample of small group homes, ICFs/MR, and foster homes had one or more medical problems *(Hill et al., 1989)*. Another study found 22% of individuals who lived in both community and institutional settings were reportedly free from substantial medical problems *(Brown, 1989)*.

Approximately 46% of people who lived in an institution and who were recommended for community placement took seizure medications *(Minihan, 1986)*, while 11% to 44% of the people who lived in the community experienced seizures *(Bradley et al., 1986; Feinstein et al., 1986; Gollay et al., 1978; Hill et al., 1989; McDonald, 1985; Springer, 1987)*. The occurrence of an active seizure disorder or receiving seizure medications among people located in both institutional and community settings ranged from 14% to 21% *(Brown, 1989; Conroy et al., 1988; Ziring, 1987)*. Other studies found individuals who resided in the community were fairly comparable in seizure activity to their peers who lived in an institutional setting *(Silverman et al., 1987)*. For example, the level of seizure activity was similar among individuals who moved to the community and those who either remained in or who were returned to an institution *(Landesman-Dwyer & Sulzbacher, 1981)*.

■ Level of Care Needed

There were mixed findings related to the level and type of medical care needs. In one study, eight percent of individuals who were institutionalized and recommended for community placement needed only routine medical care, with approximately two-thirds of the individuals rated as requiring regular specialty medical care *(Minihan, 1986)*. In contrast, another study reported that individuals targeted for deinstitutionalization and others who were recommended for continued institutional placement were both rated as needing only routine physician care *(Vitello et al., 1983)*.

Several of the studies indicated that persons in institutions, public residential facilities, and a skilled nursing facility utilized medical services more than persons in community residences or their natural homes *(Hill & Bruininks, 1981; Krauss & Seltzer, 1986; Lakin et al., in press; Seltzer & Krauss, 1984; Silverman et al., 1987)*.

Children who remained in an institution had greater medical care needs than did the children who returned to their families or to community residences. The children who were recommended for community placements had a higher need for on-call medical services than children who were already living in the community *(Seltzer & Krauss, 1984)*. However, other authors indicated that 70% of the children who moved into the community during the latter years of their study had at least one medical condition *(Mallory & Herrick, 1987)*.

It appears that only a small number of individuals who lived in institutions and in community facilities had medical needs so extensive they they needed rapid access to medical care or 24-hour medical care. One study found that 7% of the subjects needed rapid access to medical care and 2% needed 24-hour medical care *(Conroy et al., 1988)*. Another indicated that 5% of the subjects were "medically fragile" and thus needed intensive medical services *(Brown, 1989)*. One study which included persons with mental retardation who were specifically identified as having extensive medical conditions found only 4% of these individuals to be ventilator dependent *(Woodsmall, 1987)*.

There was a smaller number of people who lived in community residences and who needed rapid access to medical care. According to one study, approximately 2% of the individuals who lived in community residences needed rapid access to medical care and 1% or less required 24-hour medical personnel *(Bradley et al., 1986)*.

■ Health Related Outcomes

The health related outcomes for persons who resided in both community and institutional settings were positive. The majority of people received an appropriate frequency of medical checkups and were in good health *(Conroy et al., 1988)*. Persons with the most extensive medical conditions were judged as receiving "excellent to adequate" medical care, with the group homes rated as providing the highest quality of care *(Woodsmall, 1987)*. Only a small percentage of individuals in community residences and institutions were in need of additional medical care and health related specialty services *(Hill et al., 1989; Woodsmall, 1987)*.

Researchers found no statistically significant differences between persons in institutions, community residences, foster homes, and large private residential facilities with respect to hospitalizations and health related limitations *(Lakin et al., in press)*. Another study documented that individuals who resided in a community residence and in a skilled nursing facility had similar frequencies of general infections, but that the community residents were more likely to have ear infections, gastro-intestinal, and urinary problems *(Silverman et al., 1987)*.

The health related outcomes of individuals who were deinstitutionalized were positive. Their health was stable 9 and 18 months after their community placement *(Feinstein et al., 1986)*. Other positive outcomes, such as obtaining diagnoses for previously unrecognized medical conditions, avoiding long-term reinstitutionalization due to medical reasons, and having low rates of acute illnesses were documented either after persons with mental retardation were deinstitutionalized *(McDonald, 1985; Schor et al., 1981)*, or after they utilized a community medical service program *(Ziring, 1987)*. However, one study found comparable levels of unmet medical needs in persons who remained in community residences and in their peers who returned to an institution *(Gollay et al., 1978)*.

Other studies found persons who moved from a state institution to community residences were reportedly using the Medicaid and Medicare systems effectively with no changes in their general health indicators noted following community placement, and that few individuals had difficulties acquiring needed medical care in the community *(Conroy & Bradley, 1985)*. Although approximately 31% of the children followed were returned to the institution after their first community placement, having serious medical needs was infrequently reported as the reason for reinstitutionalization *(Mallory & Herrick, 1987)*.

Several studies indicated that persons who resided in the community had greater unmet medical service needs than did contrast groups of individuals who lived in institutions *(Jacobson & Janicki, 1985; Krauss & Seltzer, 1986)*. For example, 10% of a group of persons with severe and profound mental retardation who returned to an institution reportedly did so because their caregivers could not adequately care for their medical needs *(Landesman- Dwyer & Sulzbacher, 1981)*. Some of the obstacles to the continued community placement were related to the presence of medical problems. Specifically, residents who were perceived to have obstacles to continued group home placement had more unmet health needs than did persons with stable placements *(Jacobson & Schwartz, 1983)*.

■ Medical Care and Services Needed to Maintain Persons in the Community

Fifteen studies cited the type of medical care and services needed to retain people with mental retardation and medical needs in the community. Services cited included an organized system of primary medical care available in the immediate community on a routine and emergency basis *(Master, 1987; McGee & Menolascino, 1989; Racino & Walker, 1988; Rucker, 1987)*, ongoing primary and specialty physicians to provide continuity of care *(Burwell, 1988)*, and medical management *(McDonald, 1985)*. Other services identified were specialty services in reasonable geographic proximity *(McDonald, 1985)*, accessible comunity-based health care centers *(Pagel & Whitling, 1987)*, coordinated home health care *(University Affiliated Program-University of Medicine & Dentistry of New Jersey-Robert Wood Johnson Medical School & New Jersey Developmental Disabilities Council [UAP], 1986)*, clinical therapists and services *(UAP, 1986; Taylor, Racino, Knoll, & Lutfiyya, 1987)*, and accessible medical supports such as on call and 24-hour nursing *(McGee & Menolascino, 1989; Shoultz, 1986; Taylor et al., 1987)*.

Additional related health care supports and services suggested were the provision and maintenance of specialized medical equipment and supplies *(Bogdan, 1986; Brown, 1989; Racino & Walker, 1988; UAP, 1986; Taylor et. al., 1987)*, effective case management, interagency service coordination, and funding support for families providing home care for family members with medical needs *(Department of Health and Rehabilitative Services, 1988)*. Finally, additional trained direct care staff *(Bogdan, 1986; Minihan, 1986; Shoultz, 1986)*, transitional group homes for short term medical care and stabilization *(McGee & Menolascino, 1989)*, and home health care and services such as health care aides, home modifications, and respite care *(Bogdan, 1986; Brown, 1989; Department of Health and Rehabilitative Services, 1988; McGee & Menolascino, 1989; Racino & Walker, 1988; Shoultz, 1986; Walker, 1988)* were also idenfified as necessary to support these individuals in the community.

■ Barriers to the Provision of Community Medical Care and Services

Fifteen studies identified barriers that interfere with the delivery of community-based medical care. The first category of barriers includes initial disincentives toward the support of this population in community residences. Primary among these disincentives are inadequate per diem rates and budgets to cover the level of care/service required *(Burwell, 1988; Legislative Audit Bureau, 1989)*. As a result, there is an inadequate supply of foster and small group homes equipped to care for persons with more complex medical conditions *(Department of Health and Rehabilitative Services, 1988; Woodsmall, 1987)*.

Problems related to the funding and actual payment of medical care and services are the second category of barriers. Problems included the limited availability of funding for in-home support services *(Walker, 1988)* and medical support services that may not be covered by private insurance companies *(Walker, 1988)* or under the regular Medicaid program *(Burwell, 1988)*. In addition, the Medicaid fee structure, inefficient payment mechanisms, and delays in Medicaid reimbursements were suggested to be potential disincentives for some physicians to provide care *(Bradley et al., 1986; Garrard, 1982; Master, 1987; Schor et al., 1981; Woodsmall, 1987; Ziring, 1987)*.

The third group of barriers are related to inadequate community medical care and services. Specifically, some physicians lack formal training related to persons with mental retardation *(Buehler, Menolascino, & Stark, 1986; Dworkin, Shonkoff, Leviton, & Levine, 1979; Thomas, 1986)*. There is also a limited exchange of information between professionals in the developmental disabilities and health care fields, and direct care providers at times lack information needed to care for persons with more complex medical needs *(Shoultz & Racino, 1988)*.

The fourth category was unavailable or inaccessible medical care and services due to either geographic location *(Buehler et al., 1986; Department of Health and Rehabilitative Services, 1988)*, or poor coordination of community health care *(Woodsmall, 1987)*. For example, it was difficult to obtain generic health care for some persons who had Medicaid waivers *(Burwell, 1988)*. It was suggested that some medical service providers may be hesitant to provide care due to a lack of experience with persons with mental retardation *(Buehler et al., 1986; Garrard, 1982; Minihan, 1986)*.

■ Recommendations for Improving Community Medical Care and Services

Approximately half of the studies and reports cited recommendations to improve community medical care and services for persons with mental retardation. Sixteen recommendations were identified and categorized into five areas.

The first area focused on increasing resources. These recommendations included the development of transitional care homes *(Department of Health and Rehabilitative Services, 1988)*, pools of trained in-home care providers (Walker, 1988), and increased support services such as physical therapy *(Woodsmall, 1987)*. Additional recommendations included the provision of funding supports to enable persons with medical needs to either live with their families or in typical community residences *(Department of Health and Rehabilitative Services, 1988; Racino & Walker, 1988; Shoultz & Racino, 1988)*, sufficient respite care, medical care, and other medical support services to families *(Department of Health and Rehabilitative Services, 1988)*.

The second area included additional training and education for both medical personnel *(Buehler et al., 1986; Dworkin et al., 1979; Shoultz & Racino, 1988; Thomas, 1986)* and direct care providers *(Brown, 1989; Department of Health and Rehabilitative Services, 1988; Lakin, Hill, Bruininks, & White, 1986; McGee & Menolascino, 1989; Pagel & Whitling, 1978; Perotti & Spangler, 1983; Racino & Walker, 1988; Shoultz & Racino, 1988; Taylor et al., 1987; Ziring, 1987)*.

Improved interdisciplinary and interagency coordination of services was the third area of recommendations. Specifically, improved collaboration between professionals in the developmental disabilities and medical/health care fields *(Racino & Walker, 1988; Woodsmall, 1987)*. Moreover, improved coordination between community residences and school/vocational programs *(Perotti & Spangler, 1983)* and case management services *(Department of Health and Rehabilitative Services, 1988)* was also recommended.

The need for ongoing monitoring of the medical needs and health conditions of this population was stressed as the fourth area. The use of primary care physicians to supervise individual care and to coordinate needed specialty care *(Minihan, 1986; Woodsmall, 1987)* and more thorough monitoring by medical and health care professionals were offered as means to improve the medical care for these individuals *(Woodsmall, 1987)*. Routine monitoring of the medical conditions and health status of persons with mental retardation and annual assessments to identify potential health concerns were also suggested *(Bradley et al., 1986; Feinstein et al., 1986)*.

The final set of recommendations concerned the need for additional medical services and supports, including additional generic and specialty medical care *(Gollay et al., 1978; Hill et al., 1989; Jacobson & Janicki, 1985; Justice, Bradley, & O'Connor, 1971; Krauss & Seltzer, 1986; Rucker, 1987)*; increased nursing, occupational, and physical therapy services *(Gollay et al., 1978; Jacobson & Janicki, 1985; Woodsmall, 1987)*; and greater physician monitoring and equipment, especially for family-like and small group homes *(Woodsmall, 1987)*.

Conclusions

Although the prevalence rates of different medical conditions seen in individuals in both community residences and institutions varied across studies, these two groups were comparable in terms of existing medical conditions. However, there were specific instances where persons in institutions who were targeted for community placement had greater medical impairments than persons who have moved from those institutions into community residences. These findings seem to reflect the practice of "creaming" where individuals with more mild impairments are at times moved into community placements before other individuals who have more severe impairments.

Persons who reside in state institutions utilize service professionals, such as doctors, nurses, and other therapy providers, more frequently than do individuals who live in the community. Whether the medical conditions of persons who reside in institutions are more serious, and thus require more frequent medical care and monitoring, than are the medical conditions of their peers who live in the community remains unclear. Researchers have suggested that the higher medical service use by individuals in institutions may be related to "administrative procedures" *(Silverman et al., 1987)* or due to the service delivery model utilized in those facilities *(Lakin et al., in press)*. However, a conclusive determination of the precise factors responsible for this higher service use has not been made at this time.

People with mental retardation who reside in the community appear to be receiving adequate medical care and related health services. However, medical service shortages have been documented for some persons with mental retardation who reside both in community and institutional settings, (e.g., need for medical care and specialty services), with persons in the community at times having more unmet medical needs.

The types and range of medical care and services that are needed to support persons with mental retardation and medical needs within the community appear to be similar to the care and services that persons without handicaps might require. However, additional related supports such as case management services and funding for specific medical services and supports will also be required to assist individuals with mental retardation and medical problems to access and receive adequate medical care within the community.

A variety of barriers have been cited which may affect the quality of the medical and related services and, as a result, threaten the maintenance of this population in typical community homes. Additional education and training (for both medical personnel and direct care providers) and improved case management services and inter-agency coordination have been suggested to both improve and facilitate the delivery and monitoring of the medical care and services provided to these individuals.

A key factor that will influence whether the health of persons with mental retardation who live in community-based residences can be maintained, if not improved, after deinstitutionalization is the range and quality of medical care and support services that are made available to them. Movement into more restrictive residential placements can be decreased if support services are made available *(Polivka, Marvin, Brown, & Polivka, 1979)*. Therefore, the funding and provision of medical care and related support services to facilitate the initial placement and continued maintenance of persons with mental retardation and medical conditions in community residences are needed.

The presence of medical conditions has been cited as a rationale for the continued institutionalization of some individuals with mental retardation. Re-admissions to institutions in some cases have been due to medical and health problems *(Jacobson & Schwartz, 1983; Landesman-Dwyer & Sulzbacher, 1981; Pagel & Whitling, 1978)*. However it has been asserted that the "delivery of good health care to developmentally disabled people is a medical, not residential, issue" *(Bruininks, Hill, Lakin, & White, 1985, p.91)*. It is clear, as some of the studies reviewed in this report document that persons with significant medical complications can be placed and maintained in more normalized community settings given appropriate service supports. However, there remain significant medical barriers to community access for some indivdiuals who have complex medical problems. Within the available research there is, though, ample documentation that medical supports can be and are being provided to enable many people with extremely complex medical needs to live in community settings. A major challenge in continuing to make a place in our communities for all persons with mental retardation and related conditions will be to learn from and build on experiences of these individuals and the persons who meet their medical needs on a daily basis.

Table 1
Medical Conditions, Level of Care Needed, and Health Related Outcomes of Persons with Mental Retardation

Author (Date)	State	Number	Age	Setting	Level of MR
Bradley, Conroy, Covert, & Feinstein (1986)	NH PA	NH=149 PA=1,049	Adults & Children	Community residences (type not specified)	Borderline/Mild Moderate Severe Profound
Brown (1989)	NY	47,000	Adults & Children	Institution Community residences (type not specified) Family care home ICF/MR Day training/private schools	Borderline/Mild Moderate Severe Profound
Conroy, Feinstein, & Lemanowicz (1988)	CT	1,344	Adults & Children	Institution Long term care Group home Natural family/family like	Borderline/Mild Moderate Severe Profound
Feinstein, Lemanowicz, Spreat, & Conroy (1986)	LA	258	Adults	ICF/MR Group home Private residential facility Foster home	Borderline/Mild Moderate Severe Profound
		a. 158 (measured 9 months after placement)	---	---	---
		b. 101 (measured 9 and 18 months after placement)	---	---	---
Gollay, Freedman, Wyngaarden, & Kurtz (1978)	Nat'l	440	Adults & Children	Natural family Foster home Group home Semi-independent/independent living	Borderline/Mild Moderate Severe Profound

Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• Active seizure disorder - approx. 15% • No serious medical needs: NH=63% PA=79%	NH PA • Need visiting nurse or regular doctor visits 34% 19% • Have conditions that require rapid access to medical care 2% 2% • Need 24-hour medical care 1% 0.2%	• Not specifically addressed
•Seizure in last year - 14% • No reported medical conditions - 10% • Free from substantial medical problems - 22% • Cardiovascular and gastrointestinal conditions accounted for the largest groups of reported medical conditions.	• 5% were called "medically fragile". They had multiple medical conditions and needed intensive medical interventions	• Not specifically addressed
• Active seizure disorder - 17%	• Have life threatening condition that requires rapid access to medical care - 7% • Would not survive without 24-hour medical personnel - 2%	• The class members had seen a physician for a general medical checkup an average of 6.4 months earlier. It was reported that "it is clear that class members are receiving medical check-ups with appropriate frequency" (p.27) and were generally "in good health" (p.25).
• Current seizures - 14% • Seizures in past 6 months - 12% • Good health status - 37%	• Intermittent medical problems - 18% • Chronic ongoing problems - 46%	• Not specifically addressed.
• No serious medical needs - 76%	• Need visiting nurse or routine doctor visits - 21% • Have life threatening condition that requires immediate access to medical facilities - 3% • Medical needs were reported to be "reasonably similar" to persons without mental retardation.	• The health status of individuals remained stable after placement. At 10 months after placement only 14% of the individuals had required some type of hospital care (in the previous 4 weeks).
• Not specifically addressed	• Not specifically addressed.	• The residents remained "healthy and on the average require no more medical attention than a person who is not labeled handicapped" (p.59)
• Epilepsy - 12%	• Medical care received at least weekly - 3% • Medical care received monthly to yearly - 90%	• Only 1% of the individuals were reported as needing but not receiving medical care. • Individuals who returned to the institution and those who remained in community residences had comparable levels of unmet medical service needs. • 91% of family respondents (N=384) reported that meeting their family members medical needs was not a problem.

Table 1 (cont.)

Author (Dates)	State	Number	Age	Setting	Level of MR
Hill, Lakin, Bruininks, Amado, Anderson & Copher (1989)	Nat'l	336	Adults & Children	Foster home ICF/MR Group home	Borderline/Mild Moderate Severe Profound
Lakin, Jaskulski, Hill, Bruininks, Menke, White, & Wright (1989)	Nat'l	3,618	Adults & Children	Institution Foster home ICF/MR Group home Semi-independent living	Borderline/Mild Moderate Severe Profound
McDonald (1985)	NY	27	Adults & Children	ICF/MR	Borderline/Mild Moderate Severe Profound
Minihan (1986)	MA	229	Adults & Children	Institution (scheduled or projected for community placement)	Not specified

Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• Approximately 27% of all residents were reported to have epilepsy with no significant differences among the residents of the different residence types. • Approximately 30% of all residents had one or more medical problems. • The total percentage of residents with limitations due to health problems was approximately the same in foster and group homes (12%-17%) and slightly higher in ICFs/MR (11%-27%). • The following medical conditions were present: infections/parasites (< 2%); genitourinary problems (< 3%); digestion (< 5.2%); nervous system (< 4.4%); circulation and endocrine/ metabolism (< 7.5%); respiration (< 8.8%); and musculoskeletal and skin/ subcutis (< 9.4%).	• The total percentage of residents needing weekly to less than monthly medical care was approximately the same in foster and group homes (23%-33%) but slightly higher in ICFs/ MR (23%-40%).	• Less than 1% of the residents whose medical care use was reported had not seen a physician in the previous year. • The majority of caregivers reported that they were "very satisfied" or "quite satisfied" with the quality of medical care provided to the residents of their facilities. • Additional medical specialist services were reportedly needed by 1.6% of the facility residents.
Residence size: 3-15 beds 16+ beds • Circulatory 12.2% 10.3% • Arthritis/ rheumatism 5.1% 4.4% • Diabetes 2.0% 2.0% • Obesity 15.1% 12.4%	• Not specifically addressed.	• Not specifically addressed.
• Current seizures - 11.1% • Musculoskeletal (scoliosis) - 70% • Respiratory (frequent infections) - 25.9% • Cardiovascular (heart murmur) - 11.1% • Gastrointestinal (megacolon; esophagitis) - 14.8% • Sense organ (chronic otitis media) - 37%	• Several of the residences used 24-hour nursing services on site.	• Residents were reported to be "flourishing" and "obtaining medical services in the community that were previously unavailable to them" (p. 176). • Community residents were reported to have a low incidence of acute illnesses and emergencies.
• Neurological - 57% • Taking seizure medications - 46% • Cardiovascular - 23% • Pulmonary/respiratory - 7% • Orthopedic - 54% • Endocrine - 11% • Gastrointestinal - 22% • 99% of clients had at least one chronic medical condition.	• 8% of the individuals were rated as needing solely primary physician care. • Approximately 2/3 of the persons were rated as needing specialist care on a regular basis (especially neurologists, orthopedists, and ophthalmologists).	• Not specifically addressed.

Table 1, (cont.)

Author(Date)	State	Number	Age	Setting	Level of MR
Springer (1987)	MI	82	Adults & Children	Foster home	Borderline/Mild Moderate Severe Profound
Woodsmall (1987)	FL	110	Adults & Children	Institution Natural family ICF/MR Hospital Rehabilitation center Group home	Not specified
Vitello, Atthowe, & Cadwell (1983)	NJ	258	Adults & Children	Institution Institution (scheduled or projected for community placement)	Borderline/Mild Moderate Severe Profound
Ziring (1987)	NJ	729	Adults & Children	Institution Supervised apartments Natural family Group home	Not specified

Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• Seizures - 44% • Neurological (microcephaly) - 26% (encephalopathy) - 43% • Musculoskeletal (paralysis) - 27%	• Not specifically addressed	• 91% of the 46 persons who were reassessed showed positive changes in weight, height, tricep skinfold thickness, dietary adequacy, and/or biochemical indices. Six residents (12%) showed positive changes in all five indices and approximately 15% showed negative changes in 1 to 5 indices. • Authors concluded that the transfer of clients from institutions to foster homes did "not have adverse effects on the health and nutritional status of most clients" (p. 327).
• 33% of the persons with medical problems were rated as being minimally medically involved, 34% as moderately medically involved, and 33% as intensively medically involved. Residents assessed were part of a sample from a population of 600 clients identified as being extensively medically involved.	• Only 4% of the individuals were ventilator dependent. • Persons with the most intensive medical needs were served in all settings, but primarily in ICFs/MR.	• Additional physical and occupational therapy was needed in all settings, but especially in family and group homes. Increased physician monitoring was needed primarily in the family and group homes. More physician evaluation was needed in the residential habilitation centers. • It was reported that "in all types of settings there appeared to be both excellent and adequate provision of care" (p. 45). • The highest quality of care was reported to be in the group homes that were examined.
• No significant differences in the medical needs of persons referred for community placement and those recommended for continued institutionalization were reported.	• No significant differences were found between the two groups of residents in terms of ratings regarding medical care needed. Both groups of residents were rated as requiring no more than regular physician care.	• Not specifically addressed
• Seizures - 21% • Cardiovascular (heart defects) - 14% • Immune/infectious (Hepatitis B) - 12% (of 390 residents who were tested)	• Used a segregated service delivery model.	• None of the individuals have required long-term institutionalization for medical problems since the community medical program started. In addition, "many previously undiagnosed conditions (were) identified" (p. 207).

Table 2
Comparison of Medical Conditions, Level of Care Needed, and Health Related Outcomes of Persons with Mental Retardation Who Reside in Community Versus Institutional Settings

Author (Date)	State	Number	Age	Setting	Level of MR
Bradley, Conroy, Covert, & Feinstein (1986)	NH	Movers=164 Stayers=192	Adults & Children	Institution Community residences (type not specified)	Borderline/Mild Moderate Severe Profound
Brown (1989)	NY	Community residents=1247 Institution residents=672	Adults & Children	Institution Community residences (type not specified) ICF/MR Family care home	Borderline/Mild Moderate Severe Profound
Conroy & Bradley (1985)	PA	Institution=1154	Adults & Children	Institution	Borderline/Mild Moderate Severe Profound
		Movers=474 (from original instit. population)	Adults & Children	Community living arrangements (type not specified)	Borderline/Mild Moderate Severe Profound
Eyman, Borthwick-Duffy, Call, & White (1988)	CA	91,650	Adults & Children	Institution Community residences (type not specified) Natural family Foster home ICF/MR Skilled nursing home Health facility	Borderline/Mild Moderate Severe Profound

Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• 21% of the individuals who remained in the institution had reported seizures as compared to 10% of the persons who moved to community residences *.	• Not specifically addressed	• Not specifically addressed
• Average Developmental Disabilities Profile Medical/Health Factor Score: Institution residents=8.4, Community residents=6.0. Range: 0 (no problems) to 32 (all measured health problems and consequences). • Residents in institutions were reported as having more frequent seizures and gastrointestinal illnesses.	• Not specifically addressed	• Not specifically addressed
• 33% of the subjects had a seizure history.	• Less than 1% of the subjects had medical problems of a life-threatening nature.	• Not specifically addressed
• Not specifically addressed.	• Not specifically addressed	• The average number of daily medications prescribed to a subgroup of 207 of the movers declined after community placement , but medication reductions were also noted for the stayers. • A few individuals who moved into the community had difficulties acquiring needed medical care. • It was reported that the movers were "for the most part, using the Medicaid and Medicare services systems effectively" and "no change in general indicators of individual health following placement has been seen" (p. 316).
• The residents of skilled nursing facilities, institutions, and health facilities more often had one or more medical probelms (e.g., asthma, diabetes, heart conditions) than did individuals who lived in their natural homes, foster homes, or other community residences.	• Not specifically addressed	• A comparison of the mortality rates (during 1981-84) indicated that the highest percentage of deaths (across all levels of mental retardation) occurred in skilled nursing facilities. • Non-mobility or being tube fed was the most "stable and effective predictor of mortality" for residents 50 years of age and younger (p. 209). • Having major medical problems was determined to be the third predictor of mortality for the younger residents.

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* lly significant at the p= <.01 level.

Table 2 (cont.)

Author (Date)	State	Number	Age	Setting	Level of MR
Hill & Bruininks (1981)	Nat'l	Community facility residents =965 Public facility residents=953	Adults & Children	Institution Community residences (type not specified)	Borderline/Mild Moderate Severe Profound
Jacobson & Janicki (1985)	NY	22,256	Adults & Children	Institution Community residences (type not specified)	Severe Profound
Jacobson & Schwartz (1983)	NY	Community (stable placements)=2,742 Community (at risk placements) =491 Institut =3,092	Adults & Children	Group home Institution (recommended for community placement)	Borderline/Mild Moderate Severe Profound

Medical Conditions Present

	Comm.	Pub.	Pub. (new admit)	Pub. (re-admit)
• Seizures in last year	12.9%	22.2%	19.3%	25.1%
• Endocrine/ nutritional/ metabolic	1.8%	3.5%	1.8%	2.0%
• Circulatory	7.2%	7.6%	3.5%	2.9%
• Respiratory	2.2%	2.7%	3.2%	2.5%
• Digestive	2.5%	3.5%	2.1%	3.7%

- Approximately 20% of the individuals in each residence group had one or more chronic health problems.
- There were no statistically significant differences in the prevalence of any category of chronic health problems between the community and public residential facility residents.

Level of Care Needed

- Public facility residents were more likely to have seen a physician in the past year because of a chronic health problem than community facility residents*.
- Residents who were re-admitted to a public facility were more likely to have been treated by a physician for a temporary illness than were residents in the other groups **

Health Related Outcomes

- Approximately 90% of all resident groups had a physical examination within the previous year.

	Comm.		Instit.	
	Sev	Prof	Sev	Prof
• Cardiovascular	8%	5%	8%	3%
• Digestive	2%	4%	2%	3%
• Endocrine	3%	1%	4%	1%
• Respiratory	2%	3%	2%	2%
• Musculo-skeletal	11%	22%	9%	10%

Physically Frail(by age)

	Comm.		Instit.	
	0-21	22+	0-21	22+
• Cardiovascular	3%	2%	0%	3%
• Digestive	5%	6%	3%	2%
• Respiratory	6%	3%	4%	2%
• Musculo-skeletal	28%	30%	11%	10%

- Staff ratings indicated that 2/3 of the physically frail clients who were in institutions could be served in community settings. Physically frail residents had profound mental retardation in combination with a chronic physical/medical condition; sensory impairment; or total dependence on others for eating, toileting, and dressing.

- 18% of the young frail community residents were in need of routine medical services, as were 7% of the older frail community residents. In contrast, 1% of the young frail and 2% of the older frail individuals who resided in institutions were in need of similar services.

- The two groups of community residents were similar in terms of incidence of physical handicaps and had comparable levels of epilepsy. The individuals in the institutions who were projected for placement in group homes more often had epilepsy than did the community residents.

- Not specifically addressed

- Approximately 30% of the obstacles that threatened continued community placement were related to physical, medical, emotional, and behavioral problems of the residents.
- 67% of the individuals in jeopardy of placement failure had one or more unmet health and therapy service needs as compared to 46% of the residents with stable placements.

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* Statistically significant at the p= <.01 level.

**Statistically significant at the p= <.0001 level.

Table 2 (cont.)

Author (Date)	State	Number	Age	Setting	Level of MR
Krauss & Seltzer (1986)	MA	Community residents=219 Institution residents=866	Adults	Institution Community residences (type not specified) Natural family Foster home Skilled nursing facility Group home	Moderate Severe Profound
Lakin, Anderson, Hill, Bruininks, & Wright (in press)	Nat'l	370	Adult elderly (63+ years)	Institution Foster home Group home Large private facility (16+ beds)	Borderline/Mild Moderate Severe Profound
Landesman-Dwyer & Sulzbacher (1981)	WA	Movers=591 Stayers=1,815	Adults & Children	Institution Natural family Foster home Group home Skilled nursing home Board and care home	Severe Profound
		a. Returnees=210	Adults & Children	Institution	Severe Profound
Mallory & Herrick (1987)	NH	Movers=68 Stayers=110	Children	Institution Community residences (type not specified) Natural family Group home Foster home	Borderline/Mild Moderate Severe Profound

Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• Persons who resided in institutional settings had significantly more medical needs than did the community residents.	• Younger adults who were institutionalized received more medical services than did the younger community residents and the older adults who lived in either community residences or in institutions. • Individuals in the institutions more often needed on-call medical support than did persons in community residences.	• Community residents (especially the younger individuals) had more unmet medical needs than did persons who lived in the institutional settings.
• Residents of state institutions had a higher prevalence of several health problems than did residents in the other facilities. These included neurological, respiratory, muscle atrophy/contractures, and back problems.	• Persons in state institutions had a significantly greater frequency of nurse and physician visits than did residents in the other facilities.**	• There were no significant differences between the residents of the different facility types in terms of number of hospitalizations in the past year on in "health related limitations" (p. 13).
• There were no significant differences between severity of seizures of the persons who remained in the institution and those individuals who moved to community residences.	• Not specifically addressed	• Not specifically addressed
• Persons who returned to the institution from commuity placements were comparable to persons who had remained in the institution in regards to level of seizure activity.	• Not specifically addressed	• 10% of the residents reportedly returned due to inability of the care provider to care for their medical conditions. • Approximately 51% of the residents were returned from nursing homes, however these individuals "did not appear to have a substantial need for the specialized health provided in such facilities" (p. 189).
• From 1970-1985, children who remained in the institution were more likely to have one or more major medical conditions (45.5% of residents) which required frequent care than did children who moved to the community (26.5% of residents). * • 70% of the children who moved to the community during 1982-85 had at least one major medical condition.	• Not specifically addressed	• 30.8% of children who moved to the community were returned to the institution from their first community placement. 5% of the reasons for these returns were due to extreme medical needs.

* [illegible]y significant at the p= <.05 level.

** Statistically significant at the p= <.001 level.

Table 2 (cont.)

Author (Date)	State	Number	Age	Setting	Level of MR
Schor, Smalky, & Neff (1981)	MD	Community residents=48 Institution residents=308	Children	Institution Community residence (type not specified)	Borderline/Mild Moderate Severe Profound
Seltzer & Krauss (1984)	MA	Movers=211 Stayers=540	Children	Institution Community residences (type not specified) Natural family	Borderline/Mild Moderate Severe Profound
Silverman, Silver, Lubin, Zigman, Janicki, & Jacobson (1984)	NY	Community residents=23 Skilled nursing facility residents=115	Adults & Children	ICF/MR Skilled nursing facility	Severe Profound

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Medical Conditions Present	Level of Care Needed	Health Related Outcomes
• 31% of the community and 21% of stitution residents had a seizure sorder.	• Children received medical care within a segregated service delivery model.	• The frequency of acute care problems (e.g. infections, ear aches) was greater for the community group than in the general population. • Four out of ten community residents receiving seizure medication had the medication discontinued and three others had their medication dosages increased to therapeutic levels. • 51% of the chronic medical problems that were identified by the residence medical staff had not been previously "recognized or managed" (p. 538). • The annual number of hospital days for the entire community residents group averaged 23.6 days.
• Children who remained in the institution were more likely to have a medical condition than were children who moved either to a community residence* or to their natural homes.**	• Children in the institutions were more likely to need on-call medical support and received a greater number of medical services than did the individuals in community residences or those who lived with their families.*	• Not specifically addressed
• The community residents and skilled nursing residents did not have statistically significant differences in respiratory conditions, breathing difficulties, secretion problems, and seizure incidence in the previous six months. • Similar combinations of musculo-skeletal, respiratory and seizure disorders were present in both groups. • Skilled nursing residents experienced seizures on a less than daily basis. Community residents were more likely to have daily seizures*** and were more likely to have multiple types of seizures.****	• Comparable percentages of community residents versus skilled nursing residents received specialized medical care one or more times during the survey period. • The majority of skilled nursing facility residents saw primary physicians daily; community residents saw physicians on a less frequent basis.	• Individuals in the small community residences and persons in the skilled nursing facility had comparable frequencies of infections. • Community residents were more likely to have ear infections, urinary and gastrointestinal problems. • Six of the skilled nursing facility residents who moved to a community residence were surviving three years after placement.

* Statistically significant at the p= <.05 level.

** Statistically significant at the p= <.001 level.

*** Statistically significant at the p= <.04 level.

**** Statistically significant at the p= <.0008 level.

*Statistically significant at the p= <.05 level.

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