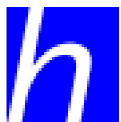
Home Care and Pharmaceuticals Division,
Health Policy and Communications Branch,
Health Canada

Analysis of Interfaces Along the Continuum of Care

Technical Report 1:
Literature Review

February 2002



Hollander Analytical Services Ltd.

**Home Care and Pharmaceuticals Division,
Health Policy and Communications Branch,
Health Canada**

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**Technical Report 1:
Literature Review**

Prepared by:

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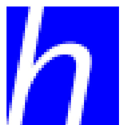

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1. INTRODUCTION

In the fall of 2000, Health Canada put out a Request for Proposal (RFP) for research on interfaces along the continuum of care. The RFP indicated that Health Canada wanted information on the continuum of care for four population groups: seniors aged 65 or older, persons with disabilities, persons requiring mental health services and children with special needs. In addition, the RFP called for a comprehensive analysis of the topic of “a continuum of care” to provide insight into how to improve the provision of health services, particularly community health services for the four above noted populations.

This project will result in a series of technical reports and an overall synthesis report. This document is the first in the series of technical reports prepared for this project. It provides a comprehensive review of the literature on models of service delivery and on issues around the continuum of care for each of the four populations, or topic areas, noted above.

2. METHODOLOGY

Extensive literature searches were conducted on the topic of models of integrated and/or coordinated service delivery systems, and services for the elderly, persons with disabilities, persons requiring mental health services and children with special needs. Searches were conducted using the HealthStar and Medline databases. The search strategies used are presented in the following set of tables.

Existing documents were also reviewed to obtain additional references.

Table 2-1: Continuum of Care Literature Search Strategy for "Models of Care" Component

Database: HealthStar
Search limits: English language articles, 1985-2001.
Number of references found: 494

Notes: /og = Organization & Administration subheading within MeSH subject headings.

SUBJECT HEADINGS	KEYWORDS
System of Care Component: delivery of health care, integrated/og preferred provider organizations/og managed care programs/og primary health care/og	SHMO: social health maintenance organization:
Linkages Component: continuity of patient care models, organizational (review articles only)	

The following terms were each searched separately, for review articles only:

SUBJECT HEADINGS	KEYWORDS
Examples of Integrated Care Component preferred provider organizations/og	GP fundholding: shmo: social health maintenance organization: integrated health system: integrated delivery system:

The following two subject headings were searched together using an AND statement, for review articles only:

SUBJECT HEADINGS	KEYWORDS
Examples of Integrated Care Component delivery of health care, integrated models, organizational	

Table 2-2: Continuum of Care Literature Search Strategy for "Elderly" Component

Database: HealthStar
Search limits: English language articles, 1985-2001.
Number of references found: 1486

Notes: /og = Organization & Administration subheading within MeSH subject headings.

SUBJECT HEADINGS	KEYWORDS
System of Care Component: delivery of health care, integrated long term care/og comprehensive health care/og home care services/og managed care/og	integrated care SHMO: social health maintenance organization: program for all inclusive care for the elderly
Home Care Component: home care services home nursing homemaker services	home health care community long term care
Facility Care Component: nursing homes homes for the aged intermediate care facilities skilled nursing facilities long term care	chronic care extended care
Elderly Component:	elderly aged aging ageing old age senior: geriatric:

Table 2-3: Continuum of Care Literature Search Strategy for "Disabled" Component

Database: HealthStar
Search limits: English language articles, 1985-2001.
Number of references found: 247

Notes: /og = Organization & Administration subheading within MeSH subject headings.

SUBJECT HEADINGS	KEYWORDS
System of Care Component: delivery of health care, integrated long term care/og comprehensive health care/og home care services/og managed care/og	integrated care SHMO: social health maintenance organization:
Home Care Component: home care services home nursing homemaker services	home health care community long term care
Facility Care Component: nursing homes homes for the aged intermediate care facilities skilled nursing facilities long term care	chronic care extended care
Disabled Component:	disabilit: disabled handicap: paraplegi: quadriplegi:

Table 2-4: Continuum of Care Literature Search Strategy for "Mental Health" Component

Database: HealthStar
Search limits: English language articles, 1985-2001.
Number of references found: 624

Notes: /og = Organization & Administration subheading within MeSH subject headings.

SUBJECT HEADINGS	KEYWORDS
System of Care Component: delivery of health care, integrated long term care/og comprehensive health care/og home care services/og managed care/og	integrated care SHMO: social health maintenance organization:
Home Care Component: home care services home nursing homemaker services	home health care community long term care
Facility Care Component: nursing homes homes for the aged intermediate care facilities skilled nursing facilities long term care	chronic care extended care
Mental Health Component: community mental health services/og mental health services/og	mental health mental disorder: psychiatr:

Table 2-5: Continuum of Care Literature Search Strategy for "Children" Component

Database: HealthStar
Search limits: English language articles, 1985-2001.
Number of references found: 674

Notes: /og = Organization & Administration subheading within MeSH subject headings.

SUBJECT HEADINGS	KEYWORDS
System of Care Component: delivery of health care, integrated long term care/og comprehensive health care/og home care services/og managed care/og	integrated care SHMO: social health maintenance organization:
Home Care Component: home care services home nursing homemaker services	home health care community long term care
Facility Care Component: nursing homes homes for the aged intermediate care facilities skilled nursing facilities long term care	chronic care extended care
Children Component:	child: children:

3. LITERATURE REVIEW ON MANAGED CARE

3.1 Introduction

Managed care is a general term (from the United States), to describe several different models of care which have some form of coordination of service provision. The Clinton model of health reform was based on a "managed care" model. A key difference between Canadian and American systems of delivering health services is the existence of Ministries of Health at the provincial level in Canada which have responsibility for the stewardship of the whole provincial system of care. Ministries of Health, until the advent of regionalization, were the primary funders, planners and managers of health services in a province. As such, Ministries could take a broader system-level perspective in developing models of service delivery across the major components or product lines of the health system.

There are no equivalent public structures like provincial Ministries of Health in the United States. American Medicare (for the elderly) and Medicaid (for the poor) are primarily insurance systems that fund service providers. This funding may be mediated through the states, and states may ask for "waivers" of Medicare and Medicaid policy in order to implement innovative demonstration projects. Only about 45 percent of health expenditures in the United States are paid for by government; the rest are paid for by private individuals, usually through some form of insurance. The insurance companies pay providers, negotiate rates and ensure that only appropriate and approved services are reimbursed.

This focus on individual providers, or provider organizations, may account for the fact that most of the American literature related to systems of care concentrates on the components of service and methods of reimbursement. There is generally little discussion of how managed care agencies actually organize their service delivery systems. There has been an ongoing evolution of managed care models over time and models continue to change and evolve. The notion underlying managed care seems to be that greater efficiencies can be obtained if services are organized in a coordinated and integrated fashion than if they operate separately and are funded through insurance based models of payment. At present, there appear to be three major clusters, or groupings of services under the broad umbrella of managed care. There are what could be referred to as traditional managed care systems which have been in place for some time or have emerged more recently. These are primarily of two types, one deals with models to reduce costs to the insurer (e.g., preferred provider organizations) while the other represents early initiatives to better integrate and coordinate physician and hospital services through health maintenance organizations. These two approaches can be organized along more traditional lines or, as they evolve, can be integrated into the two emerging, broad sectors of managed care: integrated health systems and primary care.

This chapter will provide an overview of the evolution of managed care and will then discuss integrated health systems and primary care systems.

3.2 The Evolution of Managed Care

Miller and Luft (1994) provide an excellent overview of managed care which we would recommend to any interested reader. Miller and Luft (1994) and Ennis and Meneses (1998) both note that efforts to organize services into managed care models through the early to mid-1990s were consistently challenged by professional medical organizations. Miller and Luft (1994) note:

> "...professional medical organizations adamantly opposed all forms of 'managed care'. They fought ceaselessly and successfully for decades to keep a direct, FFS relationship between physician and patient and precluded intermediaries between the two.... By 1920 the medical profession had virtually stopped corporations and government from hiring physicians and seeking competitive bids for medical care contracts.... In part, the professional associations succeeded in wresting control over the market for their skills...by threatening to expel from the association any physician who broke ranks" (pp. 445-446).

The medical associations did eventually accept the intermediary of the insurance company because it did not interfere with the fee-for-service (FFS) method of payment. Miller and Luft (1994) note that it was difficult for early health maintenance organizations (HMOs) to develop and that to do so they needed to be well financed and politically connected. They note that as late as 1970 only three million Americans were enrolled in HMOs.

The impetus to move to more integrated, managed care models came from employers and government due to the high rates of increase in medical premiums. This became a problem in the mid-to late-1970s due to the significant increase in oil prices at that time and the advent of stagflation. Consumers became more involved in investigating and participating in managed care in the early 1980s due to the high, and increasing, costs of medical insurances premiums. Due to these pressures, insurance companies, in order to maintain market share, began offering managed care plans. In addition, new entrants to the health insurance market started to offer managed care plans to compete with existing providers in local markets.

These early efforts focused primarily on a new model to decrease costs called the preferred provider organization (PPO) and the older health maintenance organization (HMO) model. Physicians had to accept HMOs because they were a reality in the health market by the 1980s and accepted PPOs because they could remain in their offices and continue to be paid on a fee-for-service basis.

In the 1990s new models of managed care evolved as part of what could be described as the "industrialization" of health care service delivery. Many different models emerged and the power of physicians to maintain the FFS model, and their overall relative power in the health industry, declined.

3.3 Managed Care Models

The following describes the most common models of managed care:

Preferred Provider Organizations (PPOs) are essentially purchasers of service. In the United States there are close links between PPOs and insurance companies and overall funding usually comes from insurance companies. To the extent that the elderly and poor are included in PPOs, revenues may also come from Medicare and Medicaid. Through their insurance policies, enrollees sign up with a PPO (there may or may not be a choice of PPOs) and receive services from a list of approved providers. The PPO will have negotiated discounted rates with a number of providers (typically hospitals, and physicians in solo or group practice). The major advantage of this system is that beneficiaries can obtain services at (often) significantly reduced prices. A key aspect of this system is that one must be able to negotiate prices for specific services. This means that providers must be able to accurately calculate the price for every type of care episode, for example, removal of an appendix, a heart transplant and so on. This would currently be very difficult to do in Canada.

Health Maintenance Organizations (HMOs) have traditionally restricted their services to that of hospitals and physicians. In contrast to PPOs, HMOs were originally established in such a way that they provided hospital and physician services directly to clients. Staff model HMOs own and operate one or more hospitals, and employ physicians on a salaried basis. While savings in PPOs accrue from the ability to negotiate reductions in rates with providers, savings in HMOs are believed to accrue through a better coordination and integration of physician services and hospital services. More recently, a number of variations of the HMO model have emerged. Some HMOs have increased the range of services provided. Some HMOs have chosen to pay physicians on a fee-for-service basis, or to contract with physician group practices. To the extent that HMOs become actual purchasers of service, and try to negotiate reduced rates, they start to become more like PPOs. However, HMOs typically maintain direct control of their hospital services and only contract for other services. Financing for HMOs generally comes through contracts with insurance companies, employers, Medicare and Medicaid. The main types of HMOs are:

- **Staff Model:** full integration of the health benefit intermediary (HBI) (i.e., the insurance company) and service providers. Doctors are salaried, the HMO is the direct employer. Hospital services may be contracted or even owned by the HMO.

- **Group Model, also called prepaid group practice (PGP):** HBI has an exclusive arrangement with one or more large, capitated medical groups. Although formally separated, the two arms work so closely together that they appear to be a single organisation.

- **Network Model:** there is a clear distinction between the HBI and provider functions. The HBI does not own, control or contract exclusively with its multiple medical groups, but each associated medical practice treats only HMO enrollees.

- **Independent Practice Association (IPA):** has two main forms. In the first model, the HBI contracts directly with multiple single-handed or small group practices on a non-exclusive basis. In the second model, the small practices combine to form an association which then contracts, again on a non-exclusive basis, with the HBI. The degree of risk-sharing varies, as does the extent of resource management. Doctors may treat FFS patients or enrollees in other HMOs (Adapted from: Steiner and Robinson, 1998, p. 183).

The trend to include a wider range of services in HMOs has led to a new type of HMO called the **Social HMO (SHMO)**. SHMOs typically include residential and community based long term care services. However, these services are generally not provided by SHMOs through direct ownership and operation. Rather, they are typically purchased from long term care facility, and home care, providers. There are also some SHMOs which cover a full range of community based mental health and alcohol and drug services, and other health services. For some models of managed care such as Social Health Maintenance Organizations one can intuit that they often have a single administrative structure, that there is a single point of entry, and that there is ongoing case management, generally by a physician.

Point-of-Service Plan (PoS): are a hybrid model, ranging from open-ended HMOs to PPOs with a gatekeeper function. The key feature is that when patients require treatment (i.e., the point of service) they can obtain it from an in- or out-of-network provider; however, there are larger co-payments for a patient who goes outside the network. Doctors on a PoS panel usually receive captitated payment; those who are not on the panel receive discounted fee-for-service payments. (Steiner and Robinson, 1998, p.183).

Miller and Luft (1994) note four dimensions of managed care models. The first dimension of managed care plans is the extent to which providers take on some of the risk from those who pay for services. This is often done through a capitation model of funding. In the United States, risk is generally taken on by physician organizations or networks of physicians. The second dimension relates to the organization and funding of physician services which vary across different models of managed care. For example, physicians can be on staff in an organization such as a staff level HMO. They may come together in large physician groups or corporations in order to spread risk. They may also combine in looser associations through risk sharing networks. Finally, physicians may also work in solo practice or in small group practices, but the number of people in these latter models is decreasing due to the industrialization of medical care. The third dimension of managed care models is the extent to which the relationship between the payer and provider are exclusive relationship or whether providers can also provide care for other organizations or continue direct FFS arrangements with patients. The fourth dimension is the extent to which out-of-network services (i.e., services provided by people not in the managed care plan in which the patient is enrolled) are covered. If they are not covered, patients may have to pay directly for out-of-network services.

Steiner and Robinson (1998) provide an overview of the common techniques for managing care in the managed care approach. Their summary is presented in Table 3-1.

Table 3-1: Common Techniques in the Managed Care Sector

Financial Incentives: may apply at organisational level or in relation to individual doctors. Include *capitation* (pre-payment regardless of eventual patient contacts) or *discounting* (volume guarantees in exchange for lower retrospective fees per contact). To influence referral behaviour, *bonuses* for low referral rates, *penalties* for high rates and *withholds* (of doctors' payments, retained against potential deficits in the referral fund). Also, financial risk-sharing incentives, including *individual risk* (calculated on basis of each doctor's performance), *ancillary risk* (assumed by doctor for outpatient tests) and *specialist risk* (when a consultant opts to share in the organisation's risk-bonus structure).

Utilisation Management and Review: case-by-case scrutiny of appropriateness designed to reduce unnecessary care. Main forms are: prospective utilisation review or *pre-authorisation* (patient or clinician must receive a judgement of the necessity of a service before it is provided; in POS or PPO, decision could be that that service is available only for an extra payment); *concurrent review* (dominant form, like assessing progress against care plans, to monitor hospital length of stay and to control use of ancillary services during treatment); *retrospective review* (original form, involving audit of individual claims and patient charts to determine doctors' treatment decisions, often by other doctors on a 'peer review panel'; if found to be inappropriate, may be linked to financial penalties); and *mandatory second opinions* (part of pre-authorisation process).

Physician Profiling: may apply at practice or individual level. Components are that: an outcome of interest (e.g., length of stay or number of procedures performed) is selected for review; the doctor's performance is compared to a norm (e.g., practice-based or guideline-based); an effort is made to change clinician's behaviour on basis of the information. Differs from utilisation management in that: it aggregates information rather than controlling use on a case-by-case basis; is considered more acceptable to physicians than utilisation management. Case mix adjustment is a crucial element in making accurate judgements of performance against norms.

Disease Management: a disease-focused integrated care package across the entire spectrum of care, including risk identification, diagnosis, preventive care and advanced-stage treatments. Seen as most useful for treatment of chronic disease. The goal is to reduce the number of patients requiring serious or extended, costly care by: assessing alternative interventions to identify and project resource use and costs; developing treatment guidelines and protocols; negotiating risk sharing and case management agreements between provider sectors working in partnership; engaging in education to modify clinical and patient behaviour. Relies upon modern information systems.

(Steiner and Robinson, 1998, p. 183-184)

Miller and Luft (1994) note the following key actors in managed care. Health care intermediaries are those organizations which intervene between the direct relationship of the service provider and the patient or client. They are essentially the organizations which pay for services with money received from premiums or, in Canada, from taxes. In the United States health care intermediaries are large insurance corporations such as Blue Cross/Blue Shield, large, often national, PPO and HMO organizations or large regional managed care organizations. In Canada, health care intermediaries would be Ministries of Health or Regional Health Authorities.

Other key players in managed care are on the provider side. Physicians may organize into a variety of network models in which physicians organize into groups to serve IPAs, HMOs, PPOs and PoS organizations They can also form into large medical groups or corporations. Large physician organization, mostly paid on a capitation basis, have increased in the numbers of clients served through the 1990s. They are essentially large groups of primary care physicians. Hospitals have also begun to amalgamate into alliances or networks, or have merged into large multi-hospital corporations to increase their power in negotiations with physicians and health care intermediaries. Finally, there has also been a growth in integrated delivery systems or integrated health systems which are often combinations of physicians and hospital groups.

With the emergence of managed care, many sectors of the health care system have had to adapt. We highlight here some key articles related to how services are adapting to the reality of managed care.

One area in which articles were found was the issue of the interface between managed care and public health and population health. The writers note that managed care organizations are typically private companies which care for people who are sick and have coverage. They point out that this is a restricted part of "health" taken in the broader context. Public health has a broad responsibility for the health of the whole population and for matters related to prevention and the determinants of health. Public health is also publicly funded How can the mandate of public health organization and managed care organizations be combined to served the greater good? There does not appear to be a consensus on this matter yet. For an exploration of this issue the interested reader is referred to Goldberg (1998), Halverson, Mays, Miller, Kaluzny and Richards (1997), Rosnick (1998) and Welton, Kantner and Katz (1997).

As noted previously, physicians have taken steps to change how they organize their services in a managed care model. Brett (1997) provides a review and critique of managed care in regard to the role of primary care physicians and hospital consultants. He points out that managed care may not be good for patients because competition between plans leads to high rates of enrollment and disenrollment. As people move from one plan to another they may have to change physicians. Brett (1997) also points out that physicians who do not meet productivity and financial goals or targets may be removed, or may remove themselves from a given plan. This points out two issues, the first is that physicians who provide more care may be dropped which raises the issue of the adequacy of the services which are provided. The second issue is that clients may lose their physician of choice.

Krentz and Hill (1994) provide an insight into the development of physician networks as a response to managed care while Paulk and Hindin (2000) provide advice for physicians as to

how to respond to, and work within, the managed care environment. They note that physicians must be creative and adaptable in their response to managed care, but must maintain their focus on the patient.

Some articles were also found on the care of children within the managed care model. Leyden (1997) notes the important role case management, using pediatric nurses, has to play in the care of infants and children. Devoe (1997) provides a critique of managed care from the perspective of a physician specializing in obstetrics and gynecology. He mirrors the points made above by primary care physicians about the adequacy of service, that is, the conflict of interests a physician faces as someone who has an ethical obligation to patients and an obligation to the funder or corporation for fiscal prudence. Devoe (1997) notes that managed care organizations "... emphasize reduced costs, limited resource utilization, improved efficiency and decreased specialty referrals. Physicians must 'play the game' or lose income or employment." (p. 263).

There were also articles related to the interface of continuing care (home care and long term care) with managed care. Romano (1994) notes that nursing homes are seeking to join various forms of health care alliances to survive in the managed care world. Stahl (1996) provides strategic advice to administrators of subacute care facilities on how to survive the managed care wave. Schifalacqua, Hook, O'Hearn and Schmidt (2000) point to the benefits case management, with physician partnering, can have on care outcomes for continuing care clients. They were able to demonstrate a decrease in the inpatient length of stay, hospital utilization and 30 day readmission rates.

Finally, in a British study which explored the reasons for the death of a particular individual, Benton (1995) points out the potential benefits of a population level case management approach. He notes that at a population level "... case management provides an opportunity for the reunification of health-care systems so as to achieve a patient-focused, needs-driven and outcome-based approach to care." (Benton, 1995, p. 25).

The current literature on the actual effectiveness of managed care is still rather mixed. Miller and Luft (1994) note that the peer-reviewed evidence on managed care is particularly weak and that there is almost no evidence on the differences in premium across types of managed care models. However, they do note that, in general, premiums tend to be somewhat lower and that the year over-year growth in premiums is generally lower for HMO type managed care models than for indemnity insurance and PPOs. They also note that managed care organizations have lower utilization rates, shorter hospital stays, greater use of less costly alternatives, greater use of preventive examinations and a comparable quality of care. Enrollees had a somewhat lower level of satisfaction with the care provided, but a fairly high level of satisfaction with the costs of service compared to insurance based models. Steiner and Robinson (1998) also found that managed care organizations had lower levels of utilization than FFS models, that premiums were lower and that the care was of equal quality. They also found that overall satisfaction was lower for managed care than insurance-based FFS models.

3.4 Emerging Models

3.4.1 Integrated Health Systems

There are a number of different types of service models which were originally called Comprehensive Health Organizations (CHOs). More recently, they have come to be called Integrated Delivery Systems (IDSs) and they are now sometimes referred to as **Integrated Health Systems (IHSs)**. The IHSs model is similar to, and expands upon, the SHMO model. The intent of IHSs is to provide a range of vertically integrated community and institutional services. There are a variety of models of IHSs with some models having a higher percentage of direct care delivery and others having more purchased services.

Integrated health systems can take many forms. However, they are generally systems of care which contain all, or a subset, of the components of the health care system. They are often referred to as vertically integrated systems of care. The basis of what exactly makes them vertical is not clear but it may have to do with the complexity of care. In vertical integration community services are at the bottom, residential services are in the middle and acute care hospitals are at the top. Thus, vertical integration refers to services which are affiliated under one management umbrella and provide different levels of care. The benefits of vertical integration are believed to be that they:

1. ... lower transaction costs between separate production processes (for example hospital acute inpatient care and subacute care) by substituting within-firm exchanges between cooperating parts of a unified organization for market transactions between separate firms, and

2. ...reduce average production costs by sharing common inputs (such as physicians and nurses) across related production processes.

(Conrad and Shortell, 1996, p.5)

There are two major types of vertically integrated systems. The more classic form is that all components are combined in a single firm with common ownership. Vertical integration can also be achieved through a network model using long term contracts, franchise agreements and other forms of formal affiliation.

Conrad and Shortell (1996) note that a central aspect of vertical integration is the value chain concept, that is the sequence of production activities which starts with raw materials and ends with a finished product. They note that in health care the value chain is equivalent to the continuum of care.

As noted above, there are many models for the structural organization and governance of integrated health systems. It is beyond the scope of this paper to discuss all possible combinations. The interested reader is referred, for more information on structure and governance, to Conrad and Shortell (1996), Riley (1994) and Savage, Taylor, Rotarius and Buessler (1997).

Conrad and Shortell (1996) note that there is some emerging evidence regarding the efficacy of integrated health systems but that the evidence is still incomplete. They also note a number of barriers which need to be overcome. Barriers include the lack of well developed and timely information systems, existing mind sets and turf protection of key actors, conflicting values between FFS approaches and corporate cost cutting, moving from the management and governance of individual organizations to an overall corporate model, and collaboration between management and staff. They also note that these issues can be countered by several key success factors such as the ability to manage change, a capacity for creativity, the willingness to make tough management decisions**,** the ability to constructively manage change by disrupting the status quo, having good communications, and being able to simultaneously differentiate functions which have grown too big and re-integrate these new parts into the system. Other success factors noted are the use of a focused strategy and supportive organizational culture, population-based planning and resource deployment, a re-engineering of governance and management structures, and a focus on core competencies and value chain alliances. It is important to also note that organizations are made up of people with different interests and values. Issues of organizational behaviour are too seldom discussed when we try to analyze what works in the health system, what does not, and why. Conrad and Shortell (1996) make clear the impact organizational behaviour can have on corporate and clinical outcomes when they state:

> Perhaps the most marked differentiation among systems will occur in the culture associated with the dominant sponsorship form-hospital, physician group, or heath plan. As documented elsewhere (Shortell et al. 1993; Shortell, Gillies, and Devers 1995), systems that continue an acute care mind set will find it extremely difficult to promote clinical integration across the continuum of care, develop the necessary outcome measures for accountability purposes, or forge significant partnerships with the community. Those systems dominated by a physician-oriented culture will make progress in relating to the community, understanding the need for long-run strategic partnerships and, perhaps, in balancing cost and service dimensions with technical quality and outcome criteria. Those dominated by a health plan perspective will understand that aspect of community related to "enrolled lives" and will make progress on some dimensions of cost and outcomes reporting, but they will not understand what it really takes to clinically integrate care across the continuum or be able to deal with community groups outside of the insured.
>
> (Conrad and Shortell, 1996, p.22)

They conclude by noting that "Focusing on community health and well-being in a serious way will be the emerging issue of the first decade of the twenty-first century." (Conrad and Shortell, 1996, p. 23).

Given the challenges noted by Conrad and Shortell, and others, a number of articles reviewed focused on the "how to" of making integrated health systems work effectively. Thompson (2000) points out five giant leaps required to integrate health services. These are: create strong links with clinical care providers, empower patients, move from push to pull (motivate clinicians to pull people into care rather than push them out), institute regular patient follow-up, and foster collaboration with clinicians and agencies. He also notes several techniques which can be used to achieve each of these steps. These techniques are to:

- set strategic priorities;
- foster multi-disciplinary involvement ;
- motivate the players or actors in the organization;
- provide proper training and weed out the non-learners; and
- make everyone accountable for measurable outcomes.

Young (1997) notes that there are many challenges to achieving integration and notes ten processes in three categories (planning processes, organizational processes, and measurement and reporting processes) to achieve greater integration. Barnsley, Lemieux-Charles and McKinney (1998) provide a detailed analysis of how to integrate continual learning into integrated delivery systems. They note techniques to bring about a shared version, facilitative leadership and clear communication channels.

As with managed care, there were a number of articles on related topics which addressed integrated health systems. Vinicor (1995) in an Irish paper discusses the implications for organizations of two competing philosophical versions about health care, the bio-medical model and the more holistic psycho social model. He notes that if these philosophical differences are not addressed people may work at cross-purposes to the detriment of both organizational and clinical effectiveness.

As noted above, most integrated health systems function on a for-profit basis. Griffith (1996) provides a discussion of a not-for-profit alternative called Integrated Health Care Organizations (IHCOs). These entities will have a community orientation rather than a membership or "covered lines" orientation. Navert (1997) discusses how mental health services can be incorporated into integrated regional delivery systems. Burns and Robinson (1997) discuss Physician Practice Management Companies (PPMCs) a form of primary care and note that they have many similarities to hospital based integrated delivery systems and, as such, pose a threat to IDSs in competing for managed care contracts. Alexander, Vaughn, Burns, Zuckerman, Anderson, Torrens and Hilberman (1996) provide a taxonomy of physician-organization arrangements in integrated health care delivery. Baker (1995) provides information on how to incorporate activity-based costing into integrated delivery systems while Kilbridge (1998) notes that importance of information systems in the relations between integrated delivery systems and physicians. Finally, Kurtenbach (1996) provides a discussion of the role and relationship of home care in regard to integrated delivery systems.

Integrated health systems have primarily been promoted by Ontario based researchers in Canada. Skelton-Green and Sunner (1997) discuss whether integrated health systems are just another fad or are here to stay. They note several pressures or drivers for greater integration of health services in Canada. These are: economic, social, organizational, technological and political drivers. They also provide a discussion of horizontal and vertical integration and on the characteristics of a Canadian version of an integrated health system. Perhaps the most active Canadian writers in this area have been Peggy Leatt and George Pink. Leatt, Pink and Naylor (1996) propose a Canadian version of an integrated health system. They note that such a system should have a defined population of enrollees of 100,000 to two million, that they would risk-share by being funded on a capitation basis, and that there would be financial incentives such as

bonuses for cost-minimization and service quality. There would be consumer choice in that money would move with the consumer as they move from one IHS to another. In their model, physicians would act as gatekeepers and managers over the full spectrum of all health care services. There would be performance-oriented governance and management, and strategic alliances with affiliated providers. The authors also note that there would be needs-based planning and information-based management, that there would be links with academia and that innovation would be fostered in what they refer to as the Canadian Integrated Delivery System (CIDS).

While the Leatt and Pink formulation is one of competitive CIDS which would have the effect of forming internal markets, other Canadian writers have recognized that regional health authorities are also forms of integrated health systems, although they do not contain all components of the health system and are structured on a geographic, rather than a rostered, basis. For example, Harrison and Verhoef (undated abstract) and Towers and Jirsch (1997) provide information on the Capital Health Authority in Edmonton.

Perhaps the most comprehensive discussion to date of a Canadian approach to IHSs is contained in a new on-line journal called Healthcare Papers. The spring 2000 edition has an article on a Canadian model of integrated healthcare in which Leatt, Pink and Guerriere update the earlier formulation by Leatt, Pink and Naylor (1996). Leatt, Pink and Guerriere (2000) note that the characteristics of successful integrated health systems are the following:

- Physicians play a key leadership role;
- The organizational structure promotes coordination;
- Primary care physicians are economically integrated;
- Practice sites provide geographic coverage;
- The system is appropriately sized;
- Physicians are organized into group practices; and
- Health plans are owned by the system.

The authors also address the issue of organization and argue that a virtual or networked model of integration is preferable to integration under one corporate organization. The authors conclude with a strategy for the development of integrated health systems in Canada. The components of the strategy are:

- Focus on the individual;
- Start with primary healthcare;
- Share information and exploit technology;
- Create virtual coordination networks at the local level;
- Develop practical needs-based funding methods; and
- Implement mechanisms to monitor and evaluate.

In the same volume of the journal a number of other experts present articles which respond to the lead article by Leatt, Pink and Guerriere (2000). Some of the critiques noted include the following points:

- Not everyone requires integrated health care and the system should be structured to recognize this.
- Integrated health systems can be best achieved through a bottom-up approach.
- The population size noted may be too big for most parts of Canada.
- There has been limited movement in the United States to full vertical integration of all health services.

3.4.2 Primary Care

There is a great deal of interest in primary care models of service delivery in Canada today. However, what is often not noted is that primary care is one of four layers in the health care system. Each of these layers is *horizontally organized*; that is, similar types of service providers operate at each level. Horizontal integration can take place in any of the four horizontal layers, for example, acute care hospitals can amalgamate into larger entities such as was done in New Brunswick. More generally, primary care is thought of as a way to integrate the practices of primary care or family physicians into practice groups, *or*, to integrate all community based health services into one broad range of health services, provided through local community clinics.

The four horizontal layers of the health system can be described as follows:

> **Primary Care:** is provided by a health care worker on a patient's first contact with the health care system and the provision of continuing care within the home or community; this includes the diagnosis, treatment and management of health problems, disease prevention and health promotion, and ongoing support, with family and community intervention where needed.
>
> **Secondary Care:** is provided by a specialist health care professional, such as a psychiatrist or general surgeon, on referral from a primary care physician, and conventionally occurs within a hospital. It can also refer to care in residential settings such as nursing homes.
>
> **Tertiary Care:** is care that requires highly specialized skills, technology, and support services, usually provided within hospitals serving a large region; and
>
> **Quaternary Care:** is highly specialized tertiary services usually available in only a small number of sites.
>
> (Hollander, Deber and Jacobs (*Eds.*), 1998, pp. 45-46.)

In some models, primary care physicians may take on the role of a gatekeeper for a wide array of services.

In Canada, primary care can refer primarily to the method of paying physicians in group practice or to the broader definition which include most community based services. This section will focus on the broader definition of primary care.

Numerous definitions of primary care have been proposed. The following are sample definitions of the broad definition of primary care:

The provision of *integrated, accessible health care services* by *clinicians* who are *accountable* for addressing a large *majority of personal health care needs*, developing a sustained *partnership* with *patients,* and practicing in the *context of family and community* (1996 Institute of Medicine definition, in Welton, Kantner and Katz, 1997, p.263).

...the provision of primary care services to a defined community, coupled with systematic efforts to identify and address the major health problems of that community through effective modification in both the primary care services and other appropriated community health progress.
(Definition by Nutteng, Wood and Conner, cited in Pullen, Edwards, Lenz and Alley, 1994 pp. 201-202).

Several authors have outlined the key characteristics of a primary care model. Pullen et al. (1994) note four major components:

- The model must adapt to the unique concerns of the community, emphasizing collective rather than individual need.
- The model must address the needs of the population for basic, entry-into-the system care for preventative, curative rehabilitation and referral services.
- The model must be comprehensive and holistic, i.e., it must provide a mechanism to address physical, psychological, sociocultural, intellectual and spiritual aspects of human need.
- Partnership and equality must exist in the model among the professional disciplines and community members.

(Pullen et al. 1994, pp. 203-204).

Nevin and Gohel (1996) note that the functional elements of a primary care system are: definition of the community; systematic identification and prioritization of major health problems in the community; interventions designed to modify identified health problems; and evaluation of the impact of these programs on targeted health problems. Knippenberg, Alihonou, Soucat, Oyegbite, Calivis, Hopwood, Niimi, Diallo, Conde and Ofosu-Amaah (1997) describe the characteristics and successful development of a primary care model in Benin and Guinea, while Rubenstein, Yano, Fink, Lanto, Simon, Graham and Robbins (1996) do so for a pilot program for Veteran's Affairs in the United States.

An excellent overview of the key elements of a primary care model is provided by the American Maternal and Child Health Bureau and is presented in Table 3-2.

Table 3-2: Primary Care Attributes

First contact care: "First contact" care is the usual entry point into the expanded health care system. The primary care provider is responsible for guiding the client to the most appropriate source of care. Within the system, the provider is contacted for all non-referred health care needs so that an informed judgment is made and guidance is given regarding the most appropriate source of care.

Continuous care: "Continuous" care refers to the longitudinal use of a regular source of care over time, regardless of the presence or absence of disease or injury. It involves a patient-provider relationship based on established trust and knowledge of the patient and his or her family. Within the system, a "health care home" is established for each child and adolescent. This home is the repository of a unified record of all health care that is provided.

Comprehensive care: "Comprehensive" care provides a continuum of essential personal health services that promote and preserve health, prevent disease, injury, and dysfunction, as well as provide care for acute and chronic illnesses and disabilities. Primary care is inclusive of the many dimensions of health beyond physical components, including the social, environment, spiritual, developmental, and intellectual aspects of health. It directly provides services needed by a substantial proportion of the population and arranges referral for services to meet needs that are relatively uncommon or rare in that population.

Coordinated care: "Coordinated" care is the linking of health care events and services. It requires the establishment of mechanisms to transfer information and the incorporation of that information into the plan of health care. Primary care has the responsibility and obligation to transfer information to and receive it from other resources that may be involved in the care of children and adolescents; and, to lead in the development and implementation of an appropriate plan for management and prevention. Coordination ensures that the more narrowly focused perspectives of the specialists are combined into a holistic view.

Community-oriented care: "Community-oriented" care takes into account the needs of a defined population. Delivery of primary care services is based on an understanding of community needs and the integration of a population perspective into clinical practice. Primary care providers are responsible for supporting public health roles and activities through epidemiologic awareness and reporting of specific health problems identified in the course of delivering personal health care services. Primary care providers contribute to and participate in community diagnosis, health surveillance, monitoring, and evaluation conducted as a routine function of public health agencies. Community-oriented care assures that the views of community members are incorporated into decisions involving policies, priorities, and plans related to the delivery of primary care.

Table 3-2: Primary Care Attributes (Continued)

Family-centred care: "Family-centred" care recognizes that the family is the major participant in the assessment and treatment of a child or adolescent. As such, families have the right and responsibility to participate individually and collectively in determining and satisfying the health care needs of their children and, in most instances, adolescents. Being family centred means that policies regarding access, availability, and flexibility take into consideration the various structures and functions of families in the community being served. Finally, it means that primary care needs to understand the nature, role, and impact of a child's health, illness, disability, or injury in terms of the family's structure, function, and dynamics.

Culturally competent care: "Culturally competent" care incorporates cultural differences into the provision of health care. Services should be acceptable to all of the groups of people in the community who may be distinguished by common values, language, world view, heritage, and institutions or beliefs about health and disease. A mechanism should be in place to represent the views of these groups and incorporate them into decisions involving policies, priorities and plans related to the delivery of services.

Source: Maternal and Child Health Bureau. Primary care for children and adolescents: Definition and attributes. Rockville, MD, U.S. Department of Health and Human Services, Health Resources and Services Administration, 1994. Included in Suntelli, Morreale, Wigton and Grason, 1996, p. 359.

There were also a number of articles related to models of primary care. Kremitske and West (1997) provide a model of patient-focused care in primary care. Lorenz, Mauksch and Gawinski (1999) note the importance of having primary care personnel collaborate with other care providers such as mental health professionals. Zinn and Mor (1998) and Kaluzny, Zuckerman and Rabiner (1998) provide an analysis of how organizational factors affect the delivery of primary care services to the elderly.

Koperski (2000) analyses whether there are lessons which can be learned from the United States for the delivery of primary care services in the United Kingdom. It should be noted that Great Britain has experimented with a model called GP Fundholding in which groups of primary care physicians receive capitated budgets to provide services to a rostered population. They also receive funds to purchase additional services for their patients such as those provided by specialist physicians in hospitals (Ham, 1996).

As noted earlier there is considerable interest in primary care in Canada. Rachlis and Kushner (1994) make a persuasive argument that a broadly based primary care model where services are provided through community health centres could save billions of dollars for the Canadian health care system. Considerable work has also been done on primary care by other Ontario based scholars. Abelson and Hutchison (1994) provide the following series of potential models which could be adopted in the Canadian context:

- Nurse-centred models include nurse-run health centres or clinics, public health nursing programs, home care programs using visiting nurses, and nursing stations located in remote areas. As such, they tend to either supplement solo practice physicians within portions of the spectrum of care or replace them in areas where physicians are hard to recruit.

- Physician-centred models are the most common primary care models in advanced industrialized societies. They emphasize care delivery by general practitioners, with other providers working in a complementary role. These models run the gamut from solo practice through to large groups. For example, many Health Maintenance Organizations (HMOs) can be seen as examples of a vertically-integrated delivery model which emphasizes primary care.

- Collaborative models have often been proposed by health reformers, but they still occupy a marginal position in most countries. Health centres are a model in which services are provided in a single location by a range of health care providers, within a community-sponsored governance structure.

(Abelson and Hutchison, 1994)

Hutchison and Abelson (1996) suggest the following to be "essential elements" of a primary care model: registration with a provider or organization, information systems, defined service standards, coordination of care, and quality improvement. Other elements deemed "promising but non-essential" include group practice, multi-disciplinary practice, general practitioner fundholding, service integration, population-based primary care, performance targets, payment by achievement, and central health records.

The Federal/Provincial/Territorial Advisory Committee on Health Services, in 1995, conducted an extensive national consultation on primary health care and specified the following "principles and elements for a reformed system": flexibility, emphasis on maintenance and improvement of health, client-centred care, patient choice of provider, accessibility/availability, evaluation and evidence-based decision making, coordination and information, inter-disciplinary team care, and accountability (Federal/Provincial/Territorial Advisory Committee on Health Services, 1996, pp. 3-6) (Hollander, Deber and Jacobs (*Eds.*), 1998, pp. 275-276).

4. LITERATURE REVIEW ON SERVICES FOR THE ELDERLY

4.1 Introduction

As usual, the largest volume of documents found in this literature review were from American writers. In past reviews of this kind conducted in the mid-1990s, this writer found numerous articles on how fragmented service delivery for the elderly is in the United States. There were numerous articles calling for more integrated care, critiques of the existing insurance based systems and articles about life care communities. This has changed over the past several years and some viable models of service delivery which overcome problems of service fragmentation have begun to emerge, and a few earlier models have now come to be used on a greater scale.

While there are fewer documents from Canada, it can be said that Canadian writers have also made a contribution to the literature in regard to describing integrated models of care for the elderly.

4.2 The American Experience

4.2.1 Existing Problems and Issues[1]

4.2.1.1 Introduction

Komisar and Niefeld (2000) note some of the problems of fragmented care which still exist in the United States. Medicare covers acute care costs for the elderly and Medicaid provides services for the poor but who gets what kind of services varies across states as there are no national standards for care. While covered for acute episodes, seniors may have to spend down their assets and impoverish themselves before they can qualify for Medicaid. The authors document that there is still a great deal of unmet need and the catastrophic burdens some families face. There are also jurisdictional issues in regard to responsibilities for the care of the elderly between state and federal governments. Komisar and Niefeld (2000) note that as the population ages issues and problems around the balance between institutional and non-institutional care, quality assurances, and the better integration of long term care and acute care will only become worse. Estes and Linkins (1997) note that the greater devaluation of responsibility for the care of the elderly may lead to a “race to the bottom” in long term care.

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[1] Much of this section is adapted from Hollander, M.J., Deber. R., Jacobs, P., Lawrence, W. (2000). *The Identification and Analysis of Incentives and Disincentives and Cost-Effectiveness of Various Funding Approaches for Continuing Care: Technical Report 1: Incentives and Disincentives in Funding Continuing Care Services - Key Concepts, Literature and Findings for Canada.* Victoria: Hollander Analytical Services Ltd.

4.2.1.2 Life Care Communities

One response to the pressures faced by Americans is to self-finance care services. It is becoming increasingly popular in the United States for individuals to buy into a system where all housing and care related services are provided for the rest of their lives. These models have several names including life-care communities and continuing care retirement communities. Membership generally requires the payment of a significant entry fee ($50,000 to $100,000 in the late 1980s) and the payment of additional monthly premiums (Leutz, 1986; American College of Physicians, 1988). These communities usually have a campus like setting. People live in single family units and have access to a range of community based services, and congregate living arrangements, as well as home nursing care. They can also receive acute care, care in long term care facilities and social services (Todorovic, Fischer and Hempler, 1997). If they need to change their physical location, for example to go into a long term care facility, they move from one setting on the campus to another, for example, from their residence to a long term care facility. These programs are essentially designed to appeal to relatively young, middle to upper income elderly who are in good health when joining and can afford the high costs of the initial fee and the ongoing monthly payments.

The advantages of this approach are that members of these communities have the security that all of their current and future acute and chronic care needs will be looked after. All care services are integrated into one seamless system and are coordinated by a professional case manager who matches care needs and services on an ongoing basis. This approach also allows individuals to select the types of communities and care programs they wish to have while they are still relatively healthy, alert and able to make such decisions in a reasoned way without the pressure of urgent care needs. Members can arrange for their needs without having to rely on the public system and are assured of high quality, integrated care for all their needs for the rest of their lives.

The disadvantages are that members may have serious problems if the organization operating their community goes bankrupt and they have care needs but no more money as it was all invested in the retirement community. With regard to the care itself, some people may object to the degree of control case managers have over what services they will provide. In addition, members only have access to providers and/or agencies on the campus. The financial incentives in this model are to provide the least costly care which may lead to under-servicing. This is particularly true if the operators of the campus got the financing wrong, or other factors arise to increase costs. These factors could result in inadequate funding for the project and under-servicing, or increases in premiums which some individuals may no longer be able to afford to pay. Finally, there are also issues of access to the communities. Only healthy, well-to-do individuals may be eligible to buy into such plans.

4.2.1.3 Private Insurance

The threat of significant costs for continuing care services in one’s old age is a concern for individuals living in the United States given the limited nature of their public continuing care services. Thus, there have been many initiatives to develop private insurance models for continuing care. To date, these initiatives have only been moderately successful. There are a

number of important issues related to the private insurance model of continuing care. Two of the better articles on this topic are “Private Long Term Care Insurance: After Coverage Restrictions is Anything Left” by Wilson and Weissert (1989) and “Long Term Care Financing: Problems and Progress” by Wiener and Hanley (1991). In addition, an excellent example of the maze of issues individuals must navigate to ensure that they actually get the care to which they, or their loved ones, are entitled is the article “Funding Pediatric Home Care” by Galten (1986).

There are a number of issues with regard to both the demand side of insurance and the supply side. With regard to the demand side, there have, in the United States, been three major barriers. The first barrier has been the inability of individuals to pay for private insurance premiums. While this is changing, most elderly persons in Canada and the United States are poor or have fairly modest incomes. They can not pay for the premiums which have to be set relatively high because, typically, such insurance is sold to elderly people and the risk of a claim is fairly high given existing utilization statistics. Wiener and Hanley (1991) note that in the United States:

> The average annual premium for the 15 top-selling individual long term care insurance products with some inflation protection is $1395 per person if purchased at age 65; it climbs rapidly to $4199 per person at age 79 [based on a survey conducted in 1990].
>
> (Wiener and Hanley, 1991, p. 72)

If one were to extrapolate these figures to Canada in the year 2000, it can be seen that they would consume a significant portion of income for a senior who only receives Old Age Security and the Guaranteed Income Supplement (OAS/GIS).

The second barrier relates to the actual purchase of insurance. While premiums could be reduced if one could buy insurance at an earlier age some companies have age limits, such that people under 50 can not purchase insurance coverage (Wilson and Weissert, 1989). Another barrier to the purchase of continuing care insurance appears to be that most individuals are not aware of the risk of needing continuing care services. Thus, while people may be prepared to purchase insurance against acute episodes of illness they appear to be less ready to purchase continuing care insurance, Wiener and Hanley state:

> People seem to be willing to accept the possibility that they will someday need to visit a doctor or be admitted to a hospital, but few people will admit that they face a significant lifetime risk of becoming disabled and using expensive nursing home or home care.
>
> (Wiener and Hanley, 1991, p. 72)

The third barrier to the purchase of insurance, in the United States, is that people think Medicare or Medigap policies cover long term care, but they do not.

On the supply side, there are issues which lead to companies having fairly restrictive policies and high premiums. Rates have to be set fairly high due to the issue of "moral hazard," that is, the increased use of services that results when individuals have insurance. This tendency to use services which are "free" or low cost at the point of care is of concern in continuing care, and particularly home care, because there are people who may be doing without care or who are

being looked after by family members (that is, not using formal paid services) who may begin to use formal services once they have insurance coverage. Thus, existing utilization rates may be under-estimates of actual utilization once people are covered by insurance. This increased risk is dealt with by charging higher premiums.

Another issue is that of adverse selection, that is, the possibility that those who are aware that they may be at risk of needing services will purchase insurance in disproportionate numbers. Thus, again, existing utilization patterns may under-represent actual service usage will not be reflective of the general population. To ensure against this risk rates have to be higher, or restrictions have to be placed on who is eligible for insurance.

Wilson and Weissert (1989) outline three key mechanisms used by insurance companies to reduce risks. Risk reduction is important in order to have affordable policies but it can have negative consequences for the purchasers of insurance. The first type of limitation is referred to as purchase and ownership requirements. These limitations have to do with the characteristics of the prospective purchaser of insurance and with premiums. Insurance companies may exclude individuals with certain types of medical histories, or certain medical conditions. Wilson and Weissert (1989) state that "beyond explicit purchase, age and exclusionary disease limitations, unwritten sales rules appear to exclude the very frail and dependent from buying policies" (p. 495). They also note that there is considerable variability in premiums across seemingly similar policies and that premiums may differ for factors such as smoking.

The second type of limitation is coverage restrictions. Wilson and Weissert (1989) note several types of coverage restrictions. There may be restrictions due to preexisting conditions. In addition to being used to exclude applicants, these conditions may affect the waiting period after which claims for preexisting conditions are honoured, for those who are covered. Payouts of claims may be restricted or denied for a number of mental health related conditions although most policies cover care for people with Alzheimer's disease. Policies in the United States may only allow coverage for care in long term care facilities if a client is hospitalized first (for some minimum period) and is then transferred to a facility.

Even if someone is insured there may be restrictions on their ability to claim benefits. For example, people may have to pay for care for a certain number of days before they are eligible for compensation by the insurance company (this is similar to the concept of deductibles). In addition, there can be innumerable requirements in the "fine print" which have to be complied with before one is eligible for compensation. Galten (1986) provides a detailed guide of how to deal with such issues in regards to receiving benefits for pediatric home care. She notes that it is important to contact the insurance company directly because insurance representatives may be unaware of recent changes to policies; to ask to speak to someone who knows the policy, and to have people read out the policy on the phone about the issue with which you are concerned; to argue for your interpretation of the policy as interpretations may differ across cases; and to complete the claim well in order to maximize the probability of being paid.

The third type of limitation is benefit restrictions. There are typically different levels of benefits for different types of services. Benefits are generally paid on a daily indemnity basis, that is, a set rate which may or may not cover the full cost of care, although some policies

reimburse actual care costs. Another benefit related restriction is the restriction of benefit coverage to a given length of time or to a maximum dollar amount.

What are the implications of the various restrictions noted above? Wilson and Weissert (1989) simulated the impact of 31 combinations of policy restrictions based on combinations of restrictions related to: prior hospitalization, mental illness, skilled- or prior skilled-care requirements, and various deductable waiting periods. The eligibility for coverage(referred to as compliance estimates in the paper, meaning the percentage who complied with, or passed, the given condition(s)) ranged from 91.9% where the only restriction was the mental health exclusion to 8.5% where a policy had all three exclusions and a 200-day deductable waiting period. The overall average compliance rate was 35.4% which meant that in their simulation, on average, only 35.4% of applicants would be deemed to be eligible for insurance coverage. Thus, 64.6% of applicants would be refused coverage. Wilson and Weissert (1989) sum up the problems with private insurance for continuing care services when they state:

> Many companies require in-person interviews with the potential beneficiary. As a result, "high risk" persons, in terms of their risk of future confinements, can potentially be identified before the sale of a policy. Companies commonly refuse to sell such persons a policy or impose a surcharge on their annual premiums (p. 505).
>
> Thus, it seems unlikely that those who are "getting through" the maze of restrictions are the ones who, in the long run, are the most in need of benefits (p. 499).

The advantages of private insurance models include that financial barriers to care, for those who purchase insurance, are reduced or eliminated. Financial assets may also be better protected for people who live in areas with income and/or means tested care programs as insurance allows them to better maintain their financial independence, to pass on assets to their children, and to avoid the process of being means tested. Finally, some individuals may prefer private insurance for ideological reasons, that is, they may prefer to pay for services themselves rather than to rely on the state for the provision of services.

The disadvantages of the private insurance model include the fact that people at the greatest risk may not be able to purchase insurance because they are too high a "risk." Skimming or selecting people who are least likely to need care may reduce premiums for such people but increase premiums for those who may need care, because premiums will not be evened out over the whole population. Once insured, people may use more services and this could result in an increase in premiums. There may be a lack of guarantees about premiums or whether or not individuals can renew their insurance. Thus, even people who have insurance could be priced out of the market or could be denied service because of their condition, just at the time they need care. Private insurance may only benefit people who are both affluent and healthy. The poor may not be able to afford premiums and the sick may be denied coverage. Finally, given the greater risks involved in covering small numbers of people, and the impact this has on premiums, the cost of private insurance provided by multiple providers may be higher than the comparable costs of a government program which allows the single payer (government) to spread risk over a much larger population. In addition, government can spread its administrative costs over a larger enrollee base, thereby reducing the proportion of overhead costs per enrollee.

4.2.2 Emerging Solutions for Integrated Care

4.2.2.1 Introduction

There appear to be three major streams of development in the United States in regard to developing more organized and integrated care for the elderly: state initiatives, the expansion of the PACE model, and Social Health Maintenance Organizations (SHMOs).

4.2.2.2 State Based Initiatives

In regard to state based models there are three noteworthy examples. The state of Arizona has a much more integrated system of care. The benefits of this integration were analyzed by William Weissert who was known throughout the 1980s for conducting research which demonstrated that home care was not a cost-effective alternative to residential care. When he studied the Arizona model he found that a more integrated system with greater targetting and review of clients brought about a system in which home care was indeed a cost-effective alternative to residential long term care (Hollander, 1999). A similar model was in place in South Carolina which was part of the large scale channelling experiments in the United States in the mid-1980s. It was the only site where it was found that home care could be a cost-effective alternative to residential care (Hollander, 1999).

Ohio’s “Options for Elderly” program (Pepe and Applebaum, 1996) shares many of the same features with Arizona and South Carolina. It has a single point of entry system with initial screening, a comprehensive assessment, levels of care, and ongoing case management, including re-assessment as needed. While not explicitly stated, it appears that this model also had some degree of single source funding and administration through county or regional area agencies on aging.

4.2.2.3 The PACE Model

Perhaps the best known model of care for the elderly in the United States is the On Lok[2] model which has come to be generalized as the Program of All-inclusive Care for the Elderly (PACE). PACE models generally operate on some form of capitation payment. PACE programs provide ongoing and relatively intensive day programs. Service is coordinated through these day programs and clients are expected to attend daily. The PACE programs provide or purchase a wide range of services for clients including acute care, long term care and residential services. The primary goal of PACE programs is to prevent the unnecessary use of hospitals and nursing homes. To be eligible, clients must be at least 55 years of age and have been deemed eligible for nursing home care, that is, clients typically have higher level care needs. PACE programs are made available through Medicare and Medicaid waivers. Those not eligible for Medicare or Medicaid pay privately. The PACE programs have generally met most of their objectives but in some cases it has proven difficult to recruit and retain clients. A PACE model has also recently been established in Edmonton, Alberta.

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[2] On Lok is a program for frail elderly persons of Chinese origin in San Francisco. Its success contributed to attempts to replicate the program under the PACE demonstration projects.

PACE programs have a form of single administration and have control over their revenues from capitation payments or user fees. Thus, they are in a position to provide or purchase needed services. PACE centres serve as the single point of entry and PACE staff conduct comprehensive assessments and provide ongoing case management and hands on care.

For an overview of the On Lok and PACE models of care the interested reader is referred to Bodenheimer (1999); Branch, Coulam and Zimmerman (1995); Cleary (1994); Eng, Pedulla, Eleazer, McCann and Fox (1997); Irvin, Massey and Dorsey (1997); Lee, Eng, Fox and Etienne (1998); Mukamel, Temkin-Greener and Clark (1998); and Pacala, Kane, Atherly and Smith (2000).

4.2.2.4 Social Health Maintenance Organizations (SHMOs)

SHMOs were developed to provide a greater range of care services, particularly for the elderly, than are generally available in HMOs. Kane, Kane, Finch, Harrington, Newcomer, Miller and Hulbert (1997) provide a discussion of the characteristics of SHMOs. These are:

- A single organizational structure at risk for providing acute care, chronic care, long term care facilities and home care.
- A coordinated case management system to authorize the benefits to clients across the range of services available.
- Controlled enrollment of a cross-section of seniors with health impairments, and more able bodied individuals.
- Financing on a pre-paid capitation basis but with member premiums and/or co-payments (p. 102).

The above characteristics are similar to those noted by other writers such as Greenberg, Leutz and Wallack (1984); Newcomer, Harrington and Kane (2000); Leutz, Abrahams, Greenlick, Kane and Prottas (1988); Leutz and Abrahams (1985); and Leutz, Greenlick and Capitman (1994). The HMO Workgroup on Care Management also outlines a number of desirable characteristics for a care system. In addition to items already covered, they focus on health promotion, wellness and greater training and education for staff and clients. The SHMO movement is still fairly small and requires further study. However, one measure of potential effectiveness is provided by Fischer, Leutz, Miller, von Sternberg and Ripley (1998) in their study on the impact on seniors of the closure of an SHMO. Seniors who were in the SHMO and became disenfranchised felt that they were “losing ground.” They switched to private-pay arrangements and relied more on informal care. The authors note that the care system for these elderly people became much less stable after the closure of the SHMO.

4.2.2.5 Other American Models of Integrated Care for the Elderly

Grason and Guyer (1995) point out the following characteristics which they note could apply to the elderly and to children: a single authority for population concerns, comprehensive service planning and coordination, a uniform core set of services and flexibility in delivery

mechanisms, and advocacy and citizen participation. Harrington, Cassel, Estes, Woolhandler and Himmelstein (1991) propose a national long term care program for the United States. They state:

> Everyone would be covered for all medically and socially necessary services under a single public plan, federally mandated and funded but administered locally. An LTC payment board in each state would contract directly with providers through a network of local public agencies responsible for eligibility determination and care coordination. Nursing homes, home care agencies, and other institutional providers would be paid a global budget to cover all operating costs and would not bill on a per-patient basis. Alternatively, integrated provider organizations could receive a capitation fee to cover a broad range of LTC and acute care services. Individual practitioners could continue to be paid on a fee-for-service basis or could receive salaries from institutional providers. Support for innovation, training of LTC personnel, and monitoring of the quality of care would be greatly augmented. For-profit providers would be compensated for past investments and phased out. Our program would add between $18 billion and $23.5 billion annually to current spending on LTC. Polls indicate that a majority of Americans want such a program and are willing to pay earmarked taxes to support it. (Harrington, Cassel, Estes, Woolhandler, and Himmelstein, 1991, pp. 302-3)

Allen and Meduna (1999) call for the development of case management, by geriatric nurses, to facilitate the interface between long term care facilities and hospitals. Ford (1994) calls on decision makers to fully appreciate home care and the role it can play to increase efficiencies in the larger health care sector. Brazil, Bolton, Ulrichsen and Knott (1998) note the benefits of a quick response service as a means of avoiding hospital placement. Pruitt (1997) calls for a new level of integration in long term care,one in which it is more integrated with community based services, and where home care can focus not only on care, but also on wellness, prevention and geriatric education. In recognition of the inter-relationships between hospitals and long term care, Phillips-Harris and Fanale (1995) call for better integration of these two sectors. Fisher and Raphael (2000) discuss how home care can be moved into managed care and the Visiting Nurse Service of New York's CHOICE program (VNS CHOICE). They note the importance of case management for a wide range of services. Home care is the hub of service delivery and multidisciplinary teams are responsible for ongoing care planning, care coordination, and the direct provision or authorization of care services. The focus of care is to maximize independence. Taking a somewhat broader perspective, Cassel, Besdine and Siegel (1999) discuss how to restructure Medicare in the United States. They note that a revised system should have a focus on: health outcomes, general prevention and preventing the deterioration of function, case management, prescription drug coverage, managed care models of delivery, the integration of acute and long term care services and protection from impoverishment due to health costs.

There is also literature from the United States on the organization of continuing care services, much of it based on the findings of various demonstration projects. Phillips-Harris and Fanale (1995) present a discussion of models for a better integration of acute care and long term care residential services which focuses on care coordination, information systems and financing. Capitman (1988) discusses the importance of case management in long term care facilities and acute care for high needs clients. In a review of the changing nature of long term care, Vladeck, Miller and Clauser (1993) note the trends to build community based systems of care and to

integrate long term care residential facilities and acute care. They also point out the emerging importance of "the development of case management, systems for client assessments, care planning and service coordination." In spite of these efforts and developments, Ford, writing in 1994, notes that there are still considerable problems in the delivery of home care in the United States. She states "although the provisions of home care services is centuries old, a most startling reality is the inability of policy makers to develop a comprehensive set of policies for the organization, financing and delivery of efficient and accountable in-home care systems" (Ford, 1994, p. 227).

4.3 International Models

Merlis (2000) provides an overview of the international experience in caring for the elderly. He notes that while most countries have universal medical coverage, long term care is often financed separately. Because many services for the elderly emerged out of the social welfare system, many countries still use a form of means testing for eligibility or require some other form of cost sharing. Another international trend has been that utilization rates for residential services have been dropping while utilization rates for home care have increased. In order to better meet client needs most countries have developed standard assessment tools, case management services, and quality assurance protocols. Merlis (2000) also notes that there is a trend toward greater integration of long term care, community based care and acute care. He also notes the importance of family caregivers.

Some material was found, in our review, on the Scandinavian countries. In a review of service delivery for the elderly in Sweden Hokenstad and Johansson (1996) note that public policy has supported the provision of home and community based services for the elderly. Sweden has a broad range of services for the elderly that includes social services, health and housing programs. Sweden has recently transferred responsibility for health from the county to the municipal level. Municipal governments now have responsibility for social services and health. The municipalities are thus responsible for funding and administrative oversight for the services in their jurisdiction. Care for the elderly includes assessment, determination of the level of care, development of care plans and case management (called care management in Sweden). While the authors are not specific it appears that there is some form of single entry as assessors go to peoples' homes to do assessments. Case management also appears to be system-level case management as case managers are seen to constitute a separate profession and have the responsibility to coordinate care services across a range of providers. In addition, there is some experimentation with a purchaser-provider split. "In this model services are purchased from different providers after the care manager has done the assessment and decided what package of care is needed" (Hokenstad and Johansson, 1996).

Cates (1995) provides an overview of trends in Norway. He presents a variety of structural schematics. These new structures are designed to: reduce the fragmentation of care; improve the continuity and quality of care; improve cost-containment efforts and enhance decision making. Local organizations have systems of care which integrate residential and community long term care with other health and social services. Cates (1994) also describes the significant changes which have taken place in Denmark, particularly the conversion of nursing homes to sheltered housing resulting in international statistics which now report that Denmark

has no nursing homes. Care is provided in sheltered housing with enhanced home based health and social supports.

In regard to the British system, Glanville (1996) in an article about the range of health care delivery in the United Kingdom, presents models of the range of care services in the community and in the overall health care system. However, she does not discuss integrating mechanisms in any degree of depth, other than to note that general practitioners (GPs) provide primary care and an access point to specialist care. There seems to be a greater reliance on physicians as the focus of care and case management in the United Kingdom. Challis, Darton, Johnson, Stone and Traske (1991) provide information about a new case management system in which case managers working out of multidisciplinary teams are focussed on providing alternatives to care in acute care hospitals.

Murashima, Zerwekh, Yamada and Tagami (1998) describe a new and innovative model of around the clock (24-hour) nursing care for the elderly in Japan. Henrard, Cassou, and Le Disert (1990) discusses some of the challenges faced in developing a model of integrated care for the elderly in France.

Two major Italian studies were found in the literature. Landi, Gambassi, Pola, Tabaccanti, Cavinato, Carbonin and Bernabei (1999) conducted a study of the effects of integrated home care services on hospital use. They found that after implementing the home care program there was a significant reduction in the number of hospitalizations compared to pre-implementation and a reduction in the number of hospital days. Bernabei, Landi, Gambassi, Sgadari, Zuccala, Mor, Rubenstein and Carbonin (1998) conducted a controlled randomized trial to study the impact of integrated care and care management for older people living in the community. They found that admission to hospitals and nursing homes occurred later and was less common, for the intervention group over the control group. The intervention group also showed improved physical function compared to controls.

4.4 The Canadian Experience

Gordon, Cheung and Wiesenthal (1990) provide a model of how acute care can be integrated with continuing care on a multi-service campus site, Baycrest in Toronto. Clarfield and Bergman (1990) discuss the impact of a primary medical care version of home care using local family physicians. A number of the people enrolled had not had a family physician previously. Bergman, Béland, Lebel, Contandriopoulos, Tousignant, Brunelle, Kaufman, Leibovich, Rodriguez and Clarfield (1997) provide a discussion of SIPA, a new system of care for the frail elderly. In SIPA, care is provided by an interdisciplinary team of health and social service professionals using case management to coordinate a wide range of health and social services. The SIPA philosophy is to respect the dignity and preferences of the elderly client. There is comprehensive funding for both health and social services for SIPA. It is the intent to eventually move to capitation funding. In terms of governance, SIPA sites operate administratively under existing local community health centres or CLSCs, but as separate programs.

Blair Richardson (1990) provides an overview of provincial home care programs in Canada and some of the key issues faced by policy makers. Reamy (1996) argues that New Brunswick's continuing care system provides cost-effective long term care. He notes that New Brunswick has a single point of entry, multi-disciplinary assessment, and ongoing case management. Reamy (1996) notes that an evaluation of a 12 month pilot project on single entry point (SEP) in 1989 and 1990 found that all client-centred, and organizational, goals were met. He states "The evaluation found that it was possible to provide alternative long-term care services to the elderly at a cost substantially below that of nursing homes, but that this care could be provided with a high level of satisfaction." A survey "... found a 97% satisfaction level with the SEP process." Based on the pilot results, SEP was introduced across New Brunswick. This resulted in a reduction of the nursing home waiting list from 1,010 in 1989 to 55 at the end of the 1993/94 fiscal year. Reamy also states that SEP was associated with a drop in the average length of stay in hospitals from 10.0 to 9.1 between the 1991/92 and 1993/94 fiscal years.

Further evidence of the efficacy of single entry is provided by DeCoster, Roos and Bogdanovic (1995). Manitoba has a single entry system with comprehensive assessment and ongoing case management. The authors found that there was much greater consistency of service utilization for nursing homes than for acute care hospitals. They conclude "A single entry system, combined with a population based planning approach, appears to provide equitable access to care across the province" (DeCoster, 1995).[3]

Brothers (1991) outlines the evolution of the single entry model in Newfoundland. This model has a single administrative structure for the service delivery system, a single point of entry, a coordinated assessment and placement process and ongoing care coordination. Staff doing the assessment and case management also provide hands on nursing care, as required. They also facilitate entry to facility care by recommending residential placement to the Regional Assessment and Placement Committees. Brothers (1991) also notes that in Gander and District, the area studied, a comprehensive database has been developed which is used for planning future resource allocation.

A federal/provincial document entitled *Guidelines for Establishing Standards for: Assessment and Placement for Adult Long-Term Care: A Single-Entry Model*, based in large part on earlier work in British Columbia, was published in 1988. This 1988 document provides a comprehensive discussion, and set of definitions, for single entry, assessment, placement and case management. It also provides a generic schematic of how a client flows through the system of care.The authors also note that a key aspect of a single entry model is that service agencies have to agree to take clients assigned to them by the assessors/case managers. They state, "The pre-condition for implementation of a single-entry model of assessment and placement is agreement between the assessing authority and the service providers...that a *standardized assessment constitutes the authority for admission into their services*" (emphasis in original) (Subcommittee on Institutional Program Guidelines, 1988, p. 12).

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[3] For an overview of the Manitoba model of continuing care readers are referred to the article "Manitoba's Single-Entry System for Long Term Care" (Shapiro, 1993).

One of the more prolific writers on integrated continuing care systems has been Hollander (Hollander 1994 and 1999; Hollander and Pallan, 1995; Hollander and Walker, 1998). He outlines a series of five best practices for organizing an integrated continuum of care for the elderly and disabled. These five best practices are:

- **Single Entry**

  Single entry provides a consistent screening mechanism which ensures that only those with appropriate needs are provided services. This increases overall systems efficiencies because it minimizes the probability that unnecessary care may be provided. In addition, single entry provides a focal point, in local communities, for "one stop shopping" for care services. This means that individuals do not have to speak to multiple sources to find out what services are available, and how they can be accessed. This increases the level of accessibility to the care system. In systems without single entry, people may not obtain care, or the most appropriate care, because of a lack of knowledge about what is available to them. Client entry is to a whole system of care, and not just to part of the system such as home care. Thus, there is a *comprehensive range* of services which are offered in the system of care.

- **Coordinated, System Level Assessment and Placement**

  Coordinated assessment and placement at the system level ensures that there is an appropriate determination of need, and that an initial care plan is developed which is most closely suited to the needs of the client. This care plan constitutes a statement of the range and approximate volume of services to be delivered by one or more types of service providers. There may be further clinical assessment and case management activities which are carried out within the agency providing actual hands-on care to the client. Based on this care plan, the client is "placed," that is, provided access to care in *any* of the components of the service delivery system whether these services are provided in institutions, the community or the client's own home. Coordinated assessment and placement increases systems efficiencies because, during this process, consideration is given to whether or not clients can be cared for in the community, as opposed to a facility. In most cases, community based care is less expensive. The system level assessment and placement process maximizes the probability that the most appropriate services are provided based on the needs of the client. Another positive feature is that the management of facility waiting lists by the assessors/case managers stops facilities from selecting the easiest to manage, or lower cost clients, sometimes referred to as "cream skimming." Finally, coordinated assessment allows for the collection of the same information for residential and community based clients on admission to the overall system of care.

- **Coordinated, Ongoing, System Level Case Management**

  Coordinated, system level case management ensures that there is regular monitoring and review of client needs and that, as needs change, care plans are adjusted to ensure that there is a continuing match between the needs of the client and the range of care services provided. This increases systems efficiencies by not allowing clients to deteriorate, from lack of regular monitoring, to the point where more costly services such as admission to an acute care hospital may be required.

- **A Single, System Level, Administrative and Funding Structure**

  A single administration for a system of health care services has several positive aspects. Government funds, and funds within regional health boards, can typically be more readily transferred between residential and community based services to maximize system efficiencies if they are in one division than if they are split between two divisions or two ministries. Similarly, at a policy level, a single administration maximizes the probability that policy issues are viewed in the context of the total continuing care system, not just one sector, such as the residential sector or the community sector. At the clinical level, a single administration maximizes the probability that care staff have a sense of the overall continuing care system, the roles that each of the service components play in the system, and, therefore, how the needs of the client can best be met within the system. At a planning level, a single administration ensures that planning and resource allocation can be done on an overall systems basis, rather than on a component by component basis.

- **A Consistent, System Level, Client Classification System**

  A consistent client classification system allows for the comparison of clients across service delivery components, by level of care, that is, an "apples to apples" comparison. This, in turn, allows analysts to determine the extent to which greater efficiencies may be possible, for example, to what extent clients who could be treated at less cost in the community are being admitted to residential care. It should be noted, however, that while community based care is typically less expensive, within each level of care, this may not always be the case. There were a few examples of home based clients in the BC system in the 1980s whose costs equalled or exceeded the costs of facility care. They continued to be treated in the community on an "exception" basis.

  Without being able to compare levels of care, it is not readily possible to determine the extent to which similar types of clients are served across service components. Without this knowledge, one cannot easily plan for an efficient and effective mix of services on a system-wide basis. For example, if all community and home based clients are at low levels of care and all facility clients are at high levels, providing more resources to community services, and reducing beds, may

only result in having more clients at low levels of care in the community while depriving those with high care needs of the facility based care they require. Conversely, if a significant proportion of community based clients are at higher levels of care, and a proportion of facility clients are at lower levels of care, the system may be capable of greater efficiencies because community and home based services have demonstrated their capacity to care for people who may be at an equivalent level of need as those in facility care. Without having comparable care levels, this type of analysis is much more difficult.

5. LITERATURE REVIEW FOR PERSONS WITH DISABILITIES

5.1 Introduction

This chapter deals primarily with services for adults with physical disabilities and cognitive impairments. Initially, a fairly significant number of references were found for people with disabilities in our literature search. However, the word disability is commonly used for children with disabilities (see Chapter 7), for disabilities related to issues of mental health (see Chapter 6), and for "the elderly and persons with disabilities" (see Chapter 4). Thus, it was found that there was a relatively modest literature specifically for adults with disabilities. In addition, there were almost no documents which specifically refer to systems of care for the disabled. Most documents related to systems of care fall under systems for "the elderly and disabled", where the elderly are by far the majority. Thus, the discussion of systems of care for adults with disabilities is still in its infancy. Similarly, there are relatively few documents on services specifically designed for adults with disabilities. All of the services provided through home care and residential care are typically available to this group but, again, tend to be covered in service descriptions for the elderly.

This chapter will discuss services used by persons with disabilities, and existing formulations of systems of care. However, the main issue which emerged in this literature review was that of self-managed care. That is, to what extent could and/or should adults with disabilities have the right to manage their own care.

5.2 Services for Persons with Disabilities

Harlid and Andersson (1993) describe the Swedish experience in regard to the organization of "domiciliary ventilation" for persons with high spinal cord injuries. Fischer (1989) describes and American program for the long term management of "ventilator-dependent patients" living at home. Many of the individuals referred to in Fischer's paper are survivors of the polio epidemic of the 1950s. Fields, Coble, Pollack and Kaufman (1991) report on the outcome of a study of 28 technology-dependent children receiving mechanical ventilation who lived at home and received case management services. The outcomes were positive but the authors do not compare them with outcomes for children who remained in hospital. Some 82% of the parents in the study indicated that the family were better off with the child at home.

Batavia (1999) provides a discussion of independent living centres, rehabilitation centres and managed care for people with disabilities. He notes that many people with disabilities, and the providers of rehabilitation services, have concerns about managed care. He also notes that the health system has not adequately addressed the concerns and needs of people with disabilities. Cherry (1983) also provides an overview of independent living arrangements. Kinsella (1999) provides an overview of telehomecare and telerehabilitation, that is, care for people using video links between clients and care providers. Finally, Rieth, Ahrens and Cummings (1995) provide a discussion of integrated disability management strategies and programs for employers.

5.3 Philosophical Issues and Models of Integrated Care

Mattson-Prince (1997) conducted a study which compared the independent living model in which persons with disabilities manage their own care and the agency-based care model in which services are provided by staff or contractors of care provider organizations. Data were collected on 29 people who received care from an agency and from 42 people who managed their own care. Mattson-Prince (1997) found that the self-managed group had significantly better health outcomes and fewer re-hospitalizations for preventable complications. The self-managed care group also had greater satisfaction. They received more hours of paid assistance but when all health related costs were calculated, their overall costs were significantly lower than for people who received their care from an agency. Benjamin, Matthias and Franke (2000) found that people with disabilities who directed their own care were significantly more satisfied, and had fewer unmet needs, than people who received agency directed care.

As noted above, there were several references on the topic of self-managed care. Nieboer (1998) discusses how families and care providers can form teams to assist people with disabilities. Thomas (1994) discusses how home care agencies are adapting to the needs of persons with disabilities. She notes that such individuals do not like the more formal medical model of care. They consider it to be the equivalent of institutional care in another setting. People with disabilities want to maximize their independence and take control of their lives, their health and their bodies. They want to be able to train their own care attendants to their own specific and particular needs, and to direct their own care. To people with disabilities the care attendant is like their arms and legs, or memory. "The services provided simply make up for the functional limitations the disability imposes" (Thomas, 1994, p. 31). People with disabilities find the rules and regulations of the formal care system to be too medically oriented and inflexible. Another problem is overall funding. Even if people with disabilities could develop better and more innovative models of care, they may not be able to bring them into reality due to fiscal constraints. Another issue is that of "transfer of function", that is, the delegation of certain tasks from one profession which has the right to perform the function to a less trained category of care provider who is not. In some cases transfer of function agreements can be implemented but the whole issue of who is allowed to do what may bring people with disabilities into conflict with professional regulations and rights of practice. Another reason persons with disabilities want to control their own care is to ensure that they have care on and ongoing basis from the same person, not from whoever is sent by the home care agency. All of the above noted desires of people with disabilities run counter to professional rights of practice and the concern of funders and care provider organizations about, liability, quality assurance, staff scheduling and a host of other issues. That is why self-managed care is such an important issue for people with disabilities.

Kafka (1998) also addresses issues related to home care and the disability community. He sets out the following principles that have been promoted by the disability community for home and community based services. The principles are:

- Maximization of choice and control over care by the care recipient.
- Availability of back-up and emergency services.
- The assurance that appropriate and sufficient services are available.

- A more unified and holistic approach to care.
- The delegation of necessary tasks to care attendants.
- The availability of volunteers.
- Improved recruiting of care attendants.
- A sliding fee schedule based on income.

(adapted from Kafka, 1998, pp. 27-28)

Kafka (1998) also provides a listing of components of agency-delivered, consumer-directed care services. This list is presented in Table 5-1.

Table 5-1: Components of Agency-Delivered, Consumer-Directed Services

No.	Component
1.	Maximum control by the consumer to select, manage, and dismiss the attendant, regardless of who the employer is.
2.	Flexibility of services. After number of hours are assessed, the consumer has the responsibility to determine when and how these services are delivered.
3.	Services are community based/noninstitutional.
4.	Services are available based on functional and health-related needs, regardless of disability and/or age.
5.	Services are as nonmedical as possible and allow for unlicensed people to perform health-related tasks through delegation or assignment.
6.	Agency can provide a pool of attendants for the consumer to select.
7.	System has a backup and emergency system that is designed by both the consumer and the agency; this could include the consumer or the agency arranging for backup.
8.	Services are provided where the client needs them (including home, work, school, church or other locations).
9.	Services are available 24 hours a day, 7 days a week.
10.	The agency can be the fiscal agent for employment responsibilities, or these responsibilities can be taken on by the consumer.
11.	Voluntary training is available on attendant management and employment responsibilities.
12.	Financial responsibility includes a copy or sliding fee scale for people of higher income.

(Kafka, 1998, p. 29)

For the interested reader, Doty, Kasper and Litvak (1996) and Simon-Rusinowitz and Hofland (1993) provide excellent overviews of the issues around self-managed care. Fricke (1998) also provides a discussion of this topic in regard to aboriginal people living in Canada.

Carter (1994) provides an overview of the implications for persons with disabilities of health reforms in New Zealand. In an American study, Holahan, Zuckerman, Evans and Rangarajan (1998) found that even though states are moving to managed care, few are enrolling the elderly and disabled. They also note the conflict between care needs and costs. Persons with disabilities require a mix of health and social services. The inter-relationships between these

sectors, which are often represented by different government ministries or departments, are often difficult and complex. Leutz (1999) provides guidance on how representatives of these sectors can work together more collaboratively, and effectively, to achieve a better overall policy environment for people with disabilities and chronic illnesses. Kane (1995) provides an excellent discussion of how the elderly, people with disabilities, and others, can receive services in group residential settings. Finally, Tanenbaum and Hurley (1995) sound a cautionary note about the challenges managed care programs will have to adequately meet the needs of persons with disabilities. They state “No matter how well intended, the actual practice of managed care for persons with disabilities at best will test the patience and ingenuity of all involved” (Tanenbaum and Hurley, 1995, p. 214).

6. LITERATURE REVIEW OF MENTAL HEALTH SERVICES

6.1 Introduction

There has been a growing literature on integrated models of mental health services over the past several years. This chapter will address innovations in service delivery for persons requiring mental health services in regard to specific services such as home care. The chapter concludes with a discussion of emerging models of integrated care.

6.2 Innovative Services

In the past, mental health services were generally provided in institutions, psychiatrists' offices, outpatient services or residential services. Several articles were found on new models such as home based services, or home care. Pessin, Lindy, Hyer and Dehm (1991) describe the range of mental health services provided by the Visiting Nurse Service in New York. They provide mobile crisis services, in-home geriatric mental health services, intensive case management services, family support programs, and case management and psychiatric services for persons with HIV/AIDS. Holland (1993) describes the provision of home based services by supportive care aides in Massachusetts. Vanderhorst, Carson and Midla (1998) describe a psychiatric home care service in Niagara, New York, which was designed to substitute for more costly institutional services. They found that 60% of patients were stable at discharge and had achieved program goals, and that 83% were medication compliant. Another description of home care services for persons needing mental health services is provided by Mayo (1997) who notes that some of the services provided in mental health home care are:

- comprehensive assessment;
- crisis intervention;
- medication administration, monitoring, and teaching;
- individual and family counseling/psychotherapy;
- health guidance and referral;
- client advocacy;
- case-management activities;
- healthcare team coordination;
- collaboration with physicians and referral sources;
- role-modeling/social skills education;
- client/family education;
- stress management; and
- competency evaluation.
- (p. 272)

Poduska (1997) describes issues related to the development of a psychiatric home care program. Hayes and Baginski (1992) describe an in-home peer counselling service for the elderly requiring mental health services, while Thompson (1999) describes a home care program in London, England. Dean and Gadd (1990) describe a home based program for the treatment of acute psychiatric illness in Birmingham, England, while Woolston, Berkowitz, Schaefer and Adnopoz (1998) describe an intensive, integrated in-home psychiatric service in Connecticut.

Descriptions of other services were also found in the literature such as assertive community treatment (Drake, McHugo, Clark, Teague, Xie, Miles and Ackerson, 1998); case management (Ellison, Rogers, Sciarappa, Cohen, and Forbess, 1995); the integration of mental health services and primary care (Dodds, Blaney, Nuehring, Blakley, Lizzotte, Potter and O'Sullivan, 2000); the psychiatric primary care nurse practitioner (Dyer, Hammill, Regan-Kubinski, Yurick and Kobert, 1998); a psychiatric mobile crisis unit (Chiu and Primeau, 1991); and a mobile clinic for the homeless requiring mental health services (Knight and Christopher, 1990). In regard to the collection of data, McDougall, Adair-Bischoff and Grant (1995) describe the development of an integrated clinical database system for a regional mental health service.

6.3 Models of Integrated Care Delivery

One of the seminal articles on organizing mental health services is a paper written by David Mechanic entitled "Strategies for Integrating Public Mental Health Services" (Mechanic, 1991). Mechanic, and other writers, note the consistent lack of integration between the major components of mental health such as community mental health, residential services and acute services (Hoge, Davidson, Griffith, Sledge and Howenstine, 1994; Mechanic, 1991; Yank, Hargrove and Davis, 1992). Mechanic (1991) identifies four generic approaches to building a public mental health system. These are "developing assertive community treatment systems, capitating mental health care, building strong local mental health authorities and developing supportive reimbursement structures (Mechanic, 1991, p. 797). He also notes the importance of integrating these four approaches in a mutually supportive manner. Mechanic suggests that having a good range of services and case management may not be enough, and that structures with only these clinical or service delivery features are "fragile" if they are not supported by a structured administrative system and appropriate financial incentives. These themes are also supported in his later work (Mechanic, 1996 and 1998).

In his discussion of assertive community treatment Mechanic (1991) notes the importance of having a range of effective community services, the importance of a continuous care team which can provide ongoing care and case management, and can serve as gatekeepers (a form of single entry) to inpatient care. In terms of funding, Mechanic argues for a global budget through capitation, which would allow for the transfer of dollars between different components of the care system such as community and institutional services. He also notes that most agencies have multiple funding streams and are unable to consolidate these funds into one overall budget. Mechanic, therefore, proposes that there should be local mental health authorities (a type of single administrative structure) at the community level which can "consolidate administrative, fiscal and clinical responsibility for care" (Mechanic, 1991, p. 799). In terms of reimbursement, Mechanic (1991) notes the importance of financial incentives to make the overall system function more appropriately. For example, he notes that some hospitals receive specific funding allocations for successfully transferring clients to community based services. On the importance of moderating fiscal imperatives with the imperatives for effective treatment, he states "Joining capitation to an assertive care program creates a potential for benefitting from the special features of the funding arrangement while maintaining a clear focus on clinical practices" (Mechanic, 1991, pp. 800-801).

In a 1994 article, Hoge and his colleagues (1994) extend the work of Mechanic (1991) and identify some additional features which should be included in a managed care system of what they call public-sector psychiatry. Hoge et al. (1994) note the importance of assertive community treatment and of case management to provide clients access to a full range of care services. They go on to more clearly define the single administrative structure of local mental health authorities. As stated above, Mechanic (1991) has noted that voluntary service coordination may be "fragile," that is voluntary coordination may not ensure a fully coordinated system. Hoge et al. (1994) note the importance of a single administrative entity which can ensure that coordination actually happens. They state "The consolidation of funding also serves to centralize authority over the range of services, enabling local mental health authorities to insist on coordination and collaboration among the various service units" (Hoge et al., 1994).

As refinements to the four core systems functions discussed by Mechanic (1991), Hoge et al. (1994) add a number of additional factors. They note the importance of a gatekeeping function at the entry points to the service system. Gatekeeping is a key component of the single entry process discussed earlier. Hoge et al. (1994) also note the importance of emphasizing the community as the locus of activity and of having a comprehensive range of care services. They state that the continuity of care is "... a multidimensional concept that includes coordination of all services offered at a given point in time, a longitudinal continuity of the way in which services are offered over time, and a consistency in the patient-provider relationships" (Hoge et al., 1994, p. 1087). Hoge et al. (1994) also go on to note the importance of maximizing economic efficiency by pooling all funds into one stream in which resources can be shifted to meet the changing needs of clients. They also identify the importance of establishing single-point accountability for care at the clinical level and for system performance at the health authority level.

Other writers echo many of these themes. Yank, Hargrove and Davis (1992) provide evidence for the effectiveness of the following characteristics: capitation based funding models, performance contracts, regional mental health authorities, utilization review and bed targets. In a study linking models of public funding and the integration of community based mental health services, Provan and Milward (1994) found that "... strong fiscal control by the state is conducive to delivery systems that are integrated through the core mental health care agency in a community, whereas weak fiscal control is more likely to result in decentralized integration among system providers" (p. 865). In outlining a new method of funding and delivery of mental health services in Philadelphia, Schinnar, Rothbard and Hadley (1989) note the importance of a mental health authority which can integrate all funding sources and shift funding as needed to better serve clients, and of intensive case management. In a study from the United Kingdom, Gask, Sibbald and Creed (1997) looked at the interface between mental health services and primary care. The authors identify a number of models in an overall "consultation-liaison" model and note that a major innovation has been the adoption of a single point of referral for multi-disciplinary care.

Smith, Hull, Hedayat-Harris, Ryder and Berger (1999) discuss the development of a vertically integrated program of services for persons with schizophrenia. They note that such a model may have both fiscal and clinical benefits. Monroe-De Vita and Mohatt (1999) provide a discussion of a continuum including intensive community based case management and a state

psychiatric hospital. Thomas and Hargett (1999) provide a description of an attempt to integrate mental health services through a holistic model based on multidisciplinary, collaborative practice. McGihon (1999) describes a program of rapid assessment and stabilization in hospital and discharge planning with follow-up in the community. In a Canadian study, Hobbs, Wilson and Archie (1999) describe an integrated self-care model of treatment for persons with chronic mental illness. Rowe, Hoge and Fisk (1998) describe a method of integrating services for mentally ill homeless people at the street level. Jones (1997) discusses another method to achieve greater integration of services, developing care pathways. Mellsop, Blair-West and Duraiappah (1997) in a New Zealand study describe an integrated care model based on three geographically defined, multidisciplinary, community care teams which provide care whether the client is in the community or in institutions. They also evaluated this new program on a before and after basis. One hospital ward (G) was integrated with the community service while another (E) was not. Following implementation of the program the cumulative length of stay for ward G was less than one half of that for ward E.

Woods, Samples, Melchiono, Keenan, Fox, Chase, Tierney, Price, Paradise, O'Brien, Mansfield, Brooke, Allen and Goodman (1998) describe a model of integrated care for HIV-positive, homeless, and at-risk youth. They state:

> The Boston HAPPENS Program model of HIV care provides a citywide network of culturally and developmentally appropriate care for adolescents, including: (a) outreach and risk-reduction counseling through professional and adult-supervised peer staff; (b) access to appropriate HIV counseling and testing support services; (c) life management counseling; (d) health status screening and services needs assessment; (e) client-focused, comprehensive, multidisciplinary care and support; (f) follow-up and outreach to ensure continuing care; and (g) integrated care and communication between providers in the metropolitan Boston area.
> (p. 39)

Rosenheck, Morrissey, Lam, Calloway, Johnsen, Goldman, Randolph, Blasinsky, Fontana, Calsyn and Teague (1998) conducted a study which found that an integrated approach to care was associated with superior housing outcomes after one year for homeless people. Le Bas, King and Block (1998), in a New Zealand study, investigated the perceptions of community mental health staff in relation to an integration of acute and community based mental health services. Staff found the new system to be beneficial, especially in regard to the continuity of patient care. Meredith, Rubenstein, Rost, Ford, Gordon, Nutting, Camp and Wells (1999) studied patterns of treatment for mental health clients in a staff or group model of managed care compared to the network model. They found that in the staff or group model, practitioners were more likely to treat patients with major depression through referral while the network model providers were more likely to prescribe anti-depressants as first-line treatment.

Hoge and Howenstine (1997) describe a series of strategies which they note may be useful for integrating mental health services. These strategies are:

- Create an umbrella organization;
- Create integrated task groups;

- Use participatory management;
- Plan strategically;
- Make use of boundary-spanning staff;
- Use team building techniques;
- Share resources; and
- Use multi-agency programming.

(p. 39)

Bickman (1996) describes the Fort Bragg managed care experiment which provides a full continuum of mental health services for children and adolescents. This continuum of care includes: a single point of entry, standardized multidisciplinary assessment, and ongoing case management.

There were a number of articles which discussed the issue of mental health “carve-outs.” Carve-outs are an American term to describe a situation in which an insurance company or managed care organization contracts separately for specialty services. Thus, for example, there could be a separate insurance contract for mental health services over and above the contract for general health services. While there is a reasonable literature on this topic, it is primarily of interest to people in the United States. The following references are provided for readers with an interest in learning more about this topic: Grazier and Eselius (1999); Huskamp (1999); Kiesler (2000); and Sabin and Daniels (1999).

Some articles were also found which provided a critique of managed care mental health services. Allen and Read (1998), in a New Zealand study, found that while physicians did see several advantages to an integrated model of care, they also saw some disadvantages including that it was time-intensive to implement, that there was a lack of adequate resources for implementation, that a rigid approach had been used and that is was unsuitable for some clients. Peak and Barusch (1999) note several issues in regard to managed care models for mental health services. Mental health can be a chronic condition, thus the need for services continues over time in a funding model designed to reduce service utilization and costs by techniques such as limiting the duration of treatment. In the United States, it may be difficult to actually obtain insurance, or adequate insurance, for mental health services. Managed care models may also put layers of intermediaries between the clinician and the client, thus reducing the level of confidentiality. Similarly, one may raise questions about the level of knowledge these intermediaries actually have when making decisions about whether or not to approve a particular type of care. Regestein (2000) provides a critical review of managed care from the perspective of the psychiatrist. He notes that managed care reverses the FFS economic incentive to prolong treatment. It encourages psychiatrists to spend less time on empathetic discussion and to use more standardized and less costly treatments. He concludes by noting that managed care will significantly change the way psychiatrists work.

Torrey (1990) provides an informative and important discussion as to why some effective service delivery systems for mental health services have not been adopted in the United States. He presents four case studies of successful programs in which there was considerable service integration and coordination. In each of these four cases, there was clear evidence of success but there was little replication of these projects and the projects themselves eventually were allowed

to “wither and die.” Torrey (1990) contends that the uncoordinated nature of the various funding systems inhibits the maintenance and expansion of innovative service models and that funding models favours hospitalization rather than community care. “Turf” issues were also seen to be at play. For example, in a project with collaboration between public mental health services and a university, Torrey (1990) notes “... the county effectively abolished a proven program in order to retain autonomy from the state-funded university system” (p. 529). He concludes by stating “Demonstration programs can demonstrate and model programs can model, but if their design, however praiseworthy, is contrary to the existing system of economic incentives, then such programs will be neither extended nor replicated” (Torrey, 1990, p. 530).

A limited but important Canadian literature also exists on characteristics of integrated mental health systems. Torrey, Bigelow and Sladen-Dew (1993) compare what they considered to be one of the best systems of mental health in Canada, the Greater Vancouver Mental Health Services (GVMHS) with service delivery systems in the 50 American states on both quality and cost. In their study they found that British Columbia “scored higher than any single state in the United States and more than twice as high as 40 states on the quality of services for seriously mentally ill individuals. . . .when ratings of quality and cost were combined, British Columbia appeared to be delivering services almost twice as good as those in New York state at about half the cost” (Torrey et al., 1993, p. 943). The researchers attribute these results to three factors. First, single source funding in the GVMHS results in less paper work and lower administrative costs. In turn, this allows for service delivery which is driven more by client needs than reimbursement eligibility. The second key factor is a clear mandate to primarily serve clients with serious mental illness. The third factor is a more comprehensive approach to service delivery. The GVMHS had a greater range of services than were found in most American states. This comprehensive approach may also be attributable to single source funding which “gives priority to patients’ needs rather than to reimbursement eligibility” (Torrey et al., 1993, p. 949).

Staff and associates of the Clarke Institute of Psychiatry have prepared discussion papers on the coordination of services and on best practices in delivering mental health services (Goering, Cochrane and Durbin, 1996; Health Systems Research Unit, 1996). They echo many of the comments noted above. Two key factors identified are “a single funding envelope that integrates diverse mental health funding streams [and] a single organization or authority responsible for management of mental health care in a defined area (Health Systems Research Unit, 1996, Chapter 9, p. 4). Other important factors are case management, a standardized care level classification system, capitation funding, performance contracting, accountability and ongoing monitoring and evaluation (Goering et al., 1996; Health Systems Research Unit, 1996). The benefits of most of these system characteristics are documented through a series of literature reviews.

7. LITERATURE REVIEW ON SERVICES FOR CHILDREN WITH SPECIAL NEEDS

7.1 Introduction

Until the mid-1990s, services for children with special needs were relatively fragmented although there were a few attempts at coordination noted in the literature. One reason for the fragmentation may have been the complexity and scope of the required services and the range of government departments with responsibility for service delivery.[4] All of these factors make greater coordination and integration more difficult. This writer and his colleagues[5] conducted a comprehensive literature review and a survey of services available for children with special needs in Canada in the mid-1990s. At that time it was clear that services were fragmented. This is reflected in the literature review which was only able to focus on the relative efficacy of different services. Thus, our previous project was able to catalogue and define the components of a comprehensive service delivery system. This current project is a natural progression as it focuses on the linkages and interfaces required to start bringing the separate parts into a more integrated *system of care*. For a comprehensive review of services for children up to the mid 1990s, the interested reader is referred to Hays, Hollander, Tan and Cloutier (1997).

Since the mid 1990s, and the advent of managed care, steps have started to be taken toward greater coordination and integration of care services for children with special needs. This chapter has three major sections. The first updates the literature on specific services for special needs children. The following section describes attempts at coordinating a limited number of service components. The final section provides an overview of emerging, comprehensive models of care delivery for children with special needs.

7.2 An Update on Services for Children With Special Needs

In the past, many children with special needs were institutionalized. Today, due to changing attitudes and technological progress, it is possible to keep children at home with the assistance of home care and home support services. A number of writers have discussed the use of home care for children with special needs.

There were a number of British writers who presented studies on the use of home care. Tatman and Woodroff (1993) provide a descriptive overview of paediatric home care in the United Kingdom. While and Dyson (2000) describe the two dominant models of home care in England, the hospital outreach model and the community model. They found that in their country-wide survey over half of the existing home care teams had been founded after 1990 and

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[4] Children need a variety of services including: institutional health services such as children's hospitals, hospital pediatric units, chronic care units and palliative care; community health and social services such as home nursing care, group homes, day care centres and buddy programs; and school based services such as special and integrated school programs; and transportation services.

[5] Hayes, V.E., McElheran, P.E. and Tan, E. (1997, October) *Evaluation of the British Columbia Ministry of Health Nursing Respite Program: Final report*. Unpublished report submitted to the B.C. Medical Services Foundation and the B.C. Ministry of Health.

that 77.8% were based in hospitals. They also note some weaknesses in the provision of care related to variability in geographic coverage, consistently low core staffing ratios, poor 24 hour coverage, and a shortage of staff skills and knowledge. Cowley and Billings (1999) provide advice on how to implement new home care programs using an action research model. They also provide a good discussion of some of the organizational issues which need to be addressed if one is to successfully start a new home care program for families and children. Jardine and Wallis (1998) provide guidelines for the discharge of ventilator assisted children from hospital to the home setting. They note that children can be considered suitable for home ventilation if they: are medically stable; have parents who understand, and are willing to carry out, the work involved in caring for such a child at home; and if it is practical and feasible for formal service providers to provide the care the child requires at home. Finally, Coe and Gallagher (1999) describe how a home care service for children operates as part of the paediatric service within a National Health Service (NHS) trust.

There were also a number of articles on home care from American writers. Feeney and Kaufman (1994) describe home care services for children with special needs in the United States. Ruth Stein (1983), one of the leaders in the field of care for special needs children, describes an early version of home care services provided by the Albert Einstein College of Medicine. Cuthbert-Allman and Burrows (1998) describe a Maternal Child Health team which provides home based services in inner city Boston. There were also some specialty home care programs in the literature. Struk and Brady (1998) describe "fur" therapy, that is home based therapy using dogs, while Woolston, Berkowitz, Schaefer and Adnopoz (1998) describe a new program of integrated, in-home psychiatric services. They note that in order to provide the best possible care, psychiatrists must be aware of the surroundings, or ecology, in which the child exists. To provide a counter balance to the push to deinstitutionalize children, Petit de Mange (1998) provides an overview of the difficulties for parents of caring for special needs children, particularly those on ventilators.

There were also a few other international studies on home care for children with special needs. Colomb, Goulet and Ricour (1998) describe a home enteral and parental nutrition program in France. Singleton (1992) describes a home based palliative care program in St. John's, Newfoundland.

There were also descriptions of other programs for children with special needs such as: early intervention programs (Cameron, 1997); services for infants and toddlers with disabilities (Saunders, 1995); mental health services in school based health clinics (Mason, 1998); case management (Smith, Layne and Garell, 1994); maternal and child services for hard to reach populations (Kuhn, 1997); managed behavioural health services for children (Cresenz, Liv and Storm, 1998); classification systems to categorize children (the National Association of Children's Hospital and Related Institutions Classification of Congenital and Chronic Health Conditions) (Muldoon, Neff and Gay, 1997); the immunization of infants (Hirano, 1998); a subacute care model for paediatrics (Grebin and Kaplan, 1995); and the use of a medical data base to improve maternal/infant continuity of care (Miller, Greenspan and Dowd, 1999).

7.3 Models Related to Partial Service Integration

There were a significant number of articles on the interface between hospitals and community, home and school based care. Hospitals have been under fiscal restraint in the United States and Canada due to their respective pressures on funding over the last decade. Thus, it should not be a surprise to see efforts to better integrate the transition of infants and children from hospitals to the community. Some of the studies reviewed were descriptive while other studies conducted cost analyses of the effectiveness of new interventions.

Racine, Stein, Belamarich, Levine, Okun, Porder, Rosenfeld and Schecter (1998) conducted a study of a vertically integrated model of care at the Albert Einstein College of Medicine in New York city. The model combined traditional inpatient and outpatient services into a vertically integrated model of primary care using four independent practice teams. The implementation of this model resulted in a decline of 0.6 days, the use of 0.62 fewer radiologic tests, and 2.68 fewer laboratory tests, per case.

York, Brown, Samuels, Finkler, Jacobsen, Persely, Swank and Robbins (1997) conducted a randomized trial of early discharge and nurse specialist transitional follow-up care for high risk childbearing women. They found that during pregnancy the intervention group had significantly fewer rehospitalizations than the control group. Diabetic women in the control group were three times more likely to have low birth weight infants. Overall, the average cost of hospital care was 44% higher for the control group.

Piehl, Clemens and Joines (2000) studied the impact of improving access to primary care services for children and their subsequent use of emergency departments in hospitals. After the implementation of the program, admission rates to emergency departments decreased by 24%. In addition, non-urgent visits decreased from an average rate of 17.9 per 1,000 population to 11.2. Liptak, Burns, Davidson and McAnarney (1998) conducted a descriptive study of 10,715 hospital admissions to look at the effect of providing comprehensive ambulatory services to children with chronic conditions. Patients with acute conditions were used as controls. The authors found that from 1984 to 1995 the mean length of stay decreased for the intervention group from 83.9 days to 10.6 days. Another perspective is provided by Kiely, Drum and Kessel (1998) who, in a literature review related to hospital stays for expectant mothers, found negative effects which were related to reduced lengths of stay. They note the following problems related to early maternal discharge: missed newborn screening, jaundice, feeding problems and missed congenital anomalies.

There were also other, more descriptive, studies in the literature related to the interface between hospitals and the community. McNamara and Sullivan (1995) describe the role of hospital based patient care coordinators in discharge planning and utilization management. Woolbright (1997) describes the use of paediatric case managers in emergency departments. Hochstadt and Yost (1989) describe a program in which medically complex children can be discharged from hospital to home for children whose parents were unable to provide the required home care. They used a foster parent model of care. Kirkhart, Steele, Pomeroy, Anguzza, French and Gates (1988) describe a case management based ventilator assisted care program to link tertiary and community care. Lowes and Davis (1997) describe the role of a specialist nurse

trained in diabetes care in keeping children with newly diagnosed diabetes out of the hospital. Wong (1991) describes a program to aid in the transition of children with complex medical needs from the hospital to home care. Finally, Farrior, Engelke, Collins and Cox (2000) describe a community based paediatric care prevention partnership which links schools, community care providers and tertiary care hospitals.

A variety of other programs linking two or more types of services were also found in the literature. Such models included: a model of integrated nursing care for children and adolescents (Bagnall, 1999); a comparison of urban versus rural home care for medically fragile children (Wheeler and Lewis, 1993); a Finnish model of care which combines intensive home care, psychology, social work and social rehabilitation to increase child protection (Niemi, 1998); a discussion of potential sites in which children with special needs can be cared for (Donaghy and Wright, 1993); nursing case management for chronically ill children (Smith, 1994); community based services for severely emotionally disturbed adolescents (Straul and Goldman, 1990); school-based health services (Armbruster, Andrews, Couenhoven and Blau, 1999); linking family input into nurses assessments of children with special needs (Papenfus and Bryan, 1998); and methods to improve collaboration between school-based health centres and school nurses (Hacker and Wessel, 1998).

7.4 Proposed Models of Comprehensive Care for Children With Special Needs

While there does not yet appear to be a consensus on what would constitute an ideal model for the delivery of health and social services to children, several writes have tried to envision such a system and/or test it out in reality.

Gray (1997) describes a managed care model for children in Michigan. Features of the proposed state-wide plan are as follows:

- All managed care organizations must provide statewide services.
- Primary care physicians or subspecialists must serve as the principle coordinating physician, essentially the gatekeeper and the medical home. This physician is chosen by the family with physician and system approval. All enrolled children must have a medical home.
- An individualized healthcare plan must be developed for each child. Family participation in this process is required in a collaborative manner with a care coordinator and the primary care physician.
- All covered services identified and approved in the individual healthcare plan are authorized and cannot be denied by the managed care organization. There should be no inappropriate restriction of access to services.
- Appropriate subspecialists and tertiary care centres must be part of the organization's network.
- Initial enrollment in the plan is voluntary. Mandatory enrollment is anticipated.
- The plan must have a medical director with CSHCN expertise.
- The plan must have a family-centered care coordinator who is either a parent of a CSHCN or is an individual with special needs.

(p. 671)

Reid, Hurtado and Starfield (1996) provide an overview of a model which contrasts primary care and managed care. They note potential problems with a managed care model applied to services for children. Ryan, Jones and Weitzman (1996) provide an article on the relation of school-based health services and managed care. They provide a model of how school-based programs can be integrated with managed care which focuses on a number of factors such as: interagency referrals and information sharing between schools and managed care organizations; provision of primary care and follow-up services on campus and the adoption by schools of capitation funding. Shneir, Kipke, Melchior and Huba (1998) provide a model of integrated care for high risk and HIV positive youth. The model is an integrated system composed of a primary care clinic, outreach, case management, mental health and substance abuse treatment services and youth empowerment and peer support.

In a poignant story, Osborn (1996) points out the links between the rules in integrated managed care models and the potentially negative consequences rules and policies can have in integrated systems if they are not strongly client focussed. He states:

> Recently, an 8-year-old girl was brought to our emergency department in the South Bronx complaining of fever, headache, and weakness. The girl and her mother were staying in a nearby shelter and had been enrolled in a health maintenance organization as part of a Medicaid managed care initiative. The family's HMO was contacted by our ED staff; a nurse receiving calls for the HMO denied emergency care, with no further instructions. We examined the girl despite the denial and made a diagnosis of meningococcal meningitis. A child's death and further contamination of an entire shelter population were narrowly averted. Had it occurred, this death would have been lamented but almost certainly would not have been attributed to the effects of managed care. (p. 225)

Waldman, Perlman and Swerdloff (1999) provide a discussion and critique of managed care as a model for children with disabilities. They note that such children use considerably more care than the average child and point out that managed care models are designed to reduce the costs of service. This may be a disadvantage for children with chronic conditions. Stroul, Pires, Katz-Leavy and Goldman (1994) analyse the implications of the American Health Security Act and provide a template for an integrated model of care for children. They note that an integrated model would have a broad array of home and community based use of alternatives to hospitalization, service provision in the least restrictive environment appropriate to the needs of the individual, organized systems of care for individuals with serious and persistent mental disorders, and mechanisms to ensure appropriate utilization (irrespective of one's health plan).

Freedman, Pierce and Reiss (1987) provide a model of a decentralized, case managed model of care for children with special needs. A copy of their model is presented here as Figure 7-1. Ogles, Trout, Gillespie and Penkert (1998) discuss an integrated managed care system which is presented in Figure 7-2.

Figure 7-1

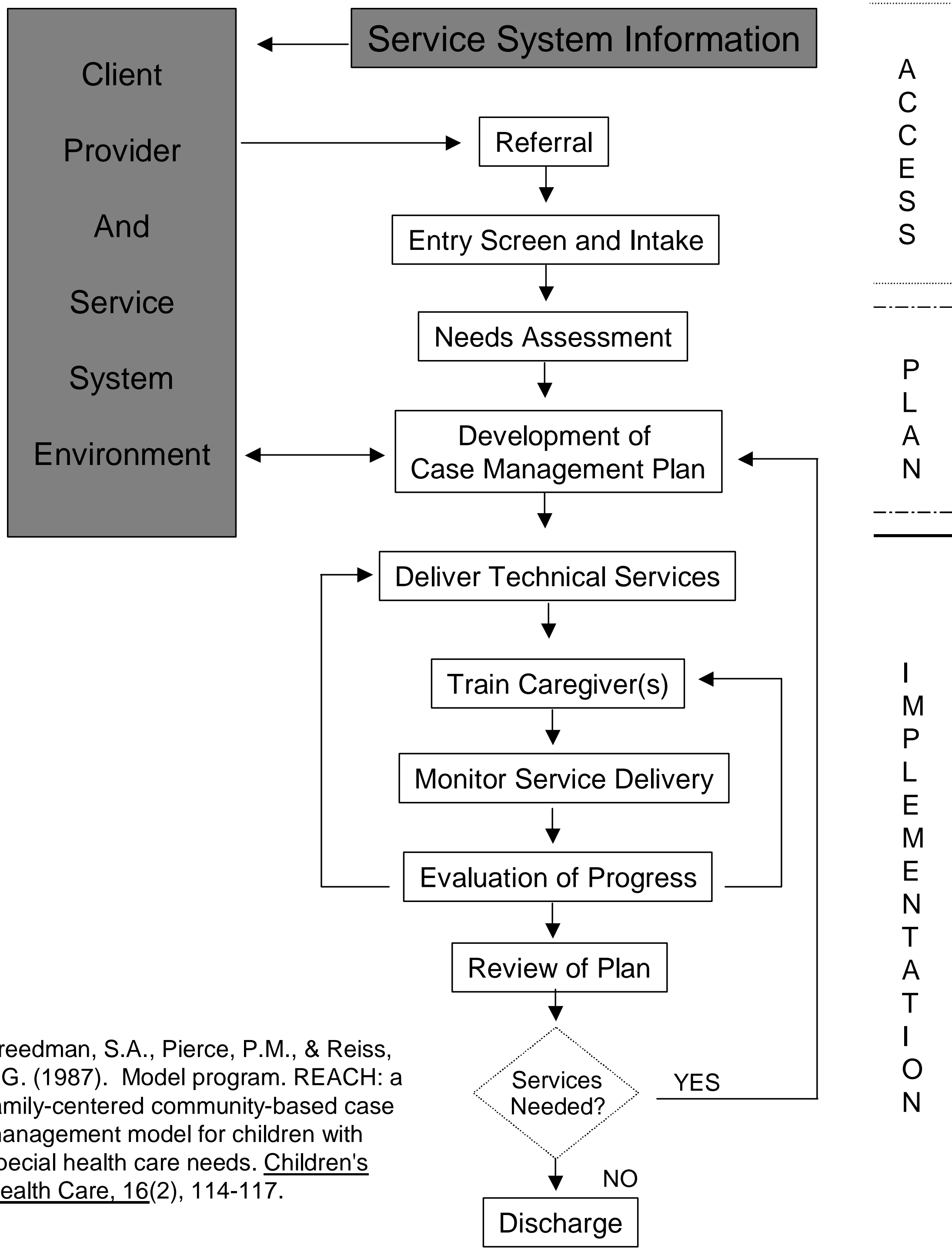
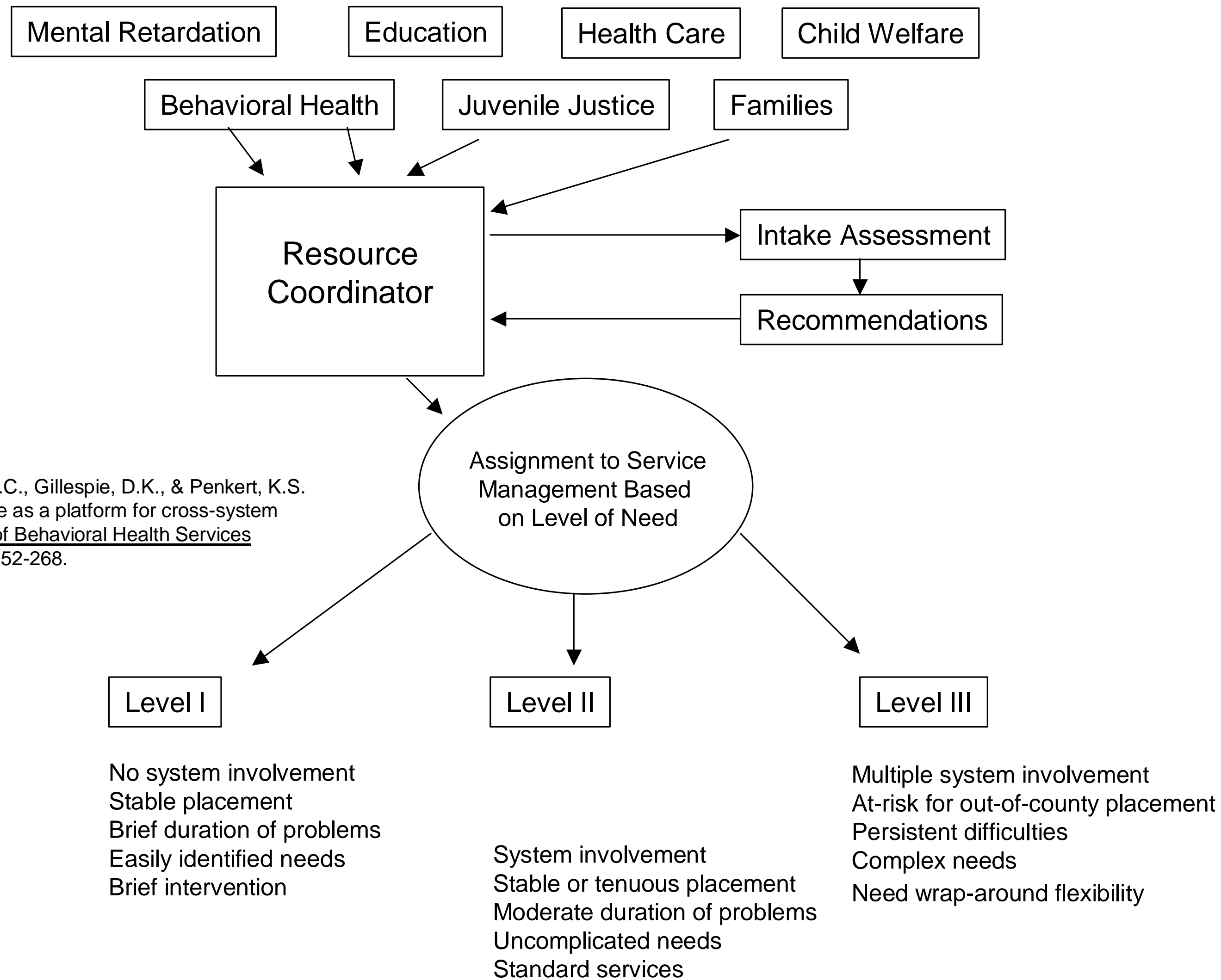


Figure 7-2



Ogles, B.M., Trout, S.C., Gillespie, D.K., & Penkert, K.S. (1998). Managed care as a platform for cross-system integration. Journal of Behavioral Health Services & Research, 25(3), 252-268.

Jessop and Stein (1994) provide the results of an evaluation of a program of outreach and comprehensive health care for children with chronic disorders. They used a pretest-posttest randomized control trial. They conclude that the "... data suggest that a comprehensive care program has measurable effects in improving traditional biomedical services and psychological and social support provided to families of children with ongoing chronic disorders." (Jessup and Stein, 1994, p.606). Horst (1995) in her discussion of a care model for low income pediatric asthma patients provides a comprehensive model of integrated services for children. The elements of this model are:

- Initial screening;
- Eligibility review;
- Needs assessment;
- Provision of access to services;
- Ongoing assessment;
- Continuing case management;
- Medical consultation;
- Continuing resource consultation;
- Continuing program assessment; and
- Ongoing in service education.

Finally, the American Academy of Pediatrics has enunciated Guiding Principles for managed care arrangements for the health care of newborns, infants, children, adolescents, and young adults. These principles are an excellent set of characteristics for an integrated model of care. As they are too lengthy to reproduce here the interested reader is referred to these Guidelines (Anonymous, 2000).

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