



Health Care for Individuals with Intellectual and Developmental Disabilities: An Integrated DD Health Home Model

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Abstract

In this chapter, we present a community-based health care model for persons with intellectual and developmental disabilities (I/DD), the DD Health Home. We explore the

background, rationale, and evolution of the model against the backdrop of the American health care system and efforts to reform it. The model addresses the triple aim of health care reform in America—better care, better health, and lower costs—for patients with I/DD who often do not have adequate access to health care. Building on the medical home concept, we show how a re-engineering of primary care practices to incorporate nurse practitioners and certain medical specialties achieves the triple aim for this population. We also describe research studies on the efficacy of the DD Health Home conducted on several iterations of the model over a 25-year period. We review clinical research that has informed practice patterns within the model and we present studies that highlight outcomes related to quality and satisfaction. Utilization studies are presented that show substantial cost savings in emergency room use and hospital admissions by patients served in the DD Health Home. We argue that the structure of the model and, especially, its care-coordination provisions account for such savings. Implications are examined for the model in a reformed health care marketplace.

1. INTRODUCTION

For policymakers and service providers in the field of intellectual and developmental disabilities (I/DD), a persistent challenge has been developing and assuring access to appropriate health care in community settings. Unfortunately, when access is possible, the health and medical services used by this group often consist of a hodgepodge of health practitioners, special clinics, and so-called “safety-net” providers. These options typically do not provide the continuity, coordination, and comprehensiveness needed by individuals with I/DD. In addition to the quality of medical care often being questionable, it has long been known that access to specialist and subspecialist care has been even more difficult for both adults and children in this group (Fisher, 2004; Havercamp, Scandlin, & Roth, 2004; Krauss, Gulley, Sciegaj, & Wells, 2003; Minihan & Dean, 1990; Reichard, Sacco, & Turnbull, 2004).

Similarly, the literature has consistently identified “barriers” to high-quality health care that confront individuals with I/DD. These barriers are related to both the individual patient and the aspects of the health system overall (Kastner & Walsh, 2006; Lewis, Lewis, Leake, King, & Lindemann, 2002; Reichard & Turnbull, 2004; US Public Health Service, 2002; Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012). Several characteristics of individuals with I/DD pose special difficulties for health care practitioners including complex medical presentations, an inability to fully participate in clinical encounters, and overriding problem behaviors. When they are insurmountable, these barriers may serve as drivers for increased utilization of long-term care services (Apgar, Lerman, & Jordan, 2003). At the same

time, additional barriers to quality care for this group arise in systemic, organizational, and payment issues inherent in the American health care system.

It is now more than a decade since the surgeon general called attention to the “gap” between the care available in the mainstream American health care system and the medical care received by individuals with what was then known as mental retardation¹ (US Public Health Service, 2002). There is now a widespread recognition that fundamental flaws remain in the nation’s health care system, and that the Patient Protection and Affordable Care Act, signed into law by President Obama in March 2010, may not solve them all.² Nonetheless, health care for individuals with I/DD must be considered within the larger context and trends of the health care system in the United States.

Over the past quarter century, at least five trends have been clear with regard to health care in America: (1) health care costs have consistently increased, (2) health care has accounted for ever-larger portions of the nation’s GDP (gross domestic product), (3) health care reform has been controversial and contentious, (4) the proportion of states’ budgets devoted to health care entitlements has consistently grown, and (5) more than 45 million Americans have little or no access to health care benefits. It is against this backdrop that individuals with I/DD enter the health care marketplace and attempt to find appropriate medical services—it can be a daunting quest.

However, prior to the Affordable Care Act, a spirit of reform was already beginning to grow in the nation’s health care sector leading to an increased recognition of what has been called the “triple aim” of health care (Berwick, Nolan, & Whittington, 2008). According to Berwick and his colleagues, the goals for American health care that define this *triple aim* are “improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations.” (p. 760)

In this chapter, we present an overview of the health care landscape for persons with I/DD, a brief review of aspects of the Affordable Care Act that relate to persons with I/DD, as well as a model of community-

¹ This paper will use the term “intellectual and developmental disabilities” or I/DD to refer to the population in question.

² At the time of this writing, the US Supreme Court had heard oral arguments on aspects of the Patient Protection and Affordable Care Act and ruled on 28 June 2012, by a 5-4 margin, that the law was constitutional. The term “Affordable Care Act” will be used to refer to this law throughout.

based health care that begins to achieve the goals of the triple aim. After a brief review of the background issues, we will describe the model and present various types of evidence for its efficacy collected over the past 25 years.



2. THE HEALTH CARE LANDSCAPE

2.1. The Medical Home

The *medical home* is a good starting point for understanding health care structures that are likely to benefit individuals with I/DD in the future. The DD Health Home described later is a specialized application of the medical home model as articulated in the literature by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and other organizations and authors (AAFP, 2007; AAP, 2002; Berenson et al., 2008; Landon, Gill, Antonelli, & Rich, 2010; Rosenthal, 2008).

The concept of the medical home was first proposed by Calvin Sia, a pediatrician in practice in Hawaii in the 1960s (Sia, Tonniges, Osterhus, & Taba, 2004). Adopted by the AAP in 1967, the concept was used initially in reference to a central location for archiving a child's medical record. In the 1980s, the Maternal and Child Health Bureau (MCHB) of the Department of Health and Human Services, seeking to improve the care provided to children with special health care needs and their families, proposed that pediatricians provide family-centered, community-based, and coordinated care. In its 2002 policy statement, the AAP expanded the medical home concept to incorporate the operational characteristics identified by MCHB as vital to the health of children with special health care needs—that health care needed to be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective (AAP, 2002).

At the same time, health care policymakers had come to realize that the lack of adequate primary care services led to an increase in episodic care provided in emergency rooms and hospital clinics, and an overreliance on more expensive specialty services. For example, it was reported that health care access for nearly half of Medicaid beneficiaries with disabilities was through hospital outpatient departments, including emergency rooms (Davidson & Somers, 1998). Access to health care through hospitals has been common because many individuals on Medicaid have not been able to receive routine health care from community-based primary care providers.

Lack of access has been especially problematic for persons with I/DD resulting in the service gap identified in the Surgeon General's report.

As concerns about primary care grew in America (Bodenheimer, Grumbach, & Berenson, 2009; Bodenheimer & Pham, 2010; Phillips & Bazemore, 2010), the interests of policymakers and health care providers became aligned and they aimed to strengthen the role of primary care providers. Strengthening primary care was seen as a way to reduce health care costs and improve quality (Berenson et al., 2008). As these powerful ideas spread, in addition to the AAP, the AAFP and the American College of Physicians (ACP) developed their own models for improving patient care under the rubrics of the "patient-centered medical home" (AAFP) or the "advanced medical home" (ACP, 2006).

In March 2007, the AAP joined with the AAFP, the ACP, and the American Osteopathic Association to publish a joint set of principles on the patient-centered medical home (AAFP, 2007). This consensus statement describes the principles of the medical home. These principles include access to a personal physician in a physician-directed medical practice, a whole person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment.

Thus, the medical home is not a place; rather, it is an approach to primary health care delivery that provides individuals with timely, well-organized care and enhanced access while reducing service disparities due, for example, to disability. The medical home concept emphasizes care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. It also promotes equity in health care by integrating services and supports that assure individuals receive the right kind of care, when they need it, in an appropriate setting (Beal, Doty, Hernandez, Shea, & Davis, 2007).

A key element of the medical home is the capacity to coordinate care. For persons with developmental disabilities, this coordination of care is vitally important because of the frequency of comorbid conditions. Several entities need to be coordinated including primary care practitioners, medical specialists, tertiary health care providers such as hospitals and rehabilitation centers, allied health professionals, and ancillary services including durable medical equipment (DME) vendors and pharmacies (AAP, 2005; Criscione, Walsh, & Kastner, 1995; Kastner, Walsh, & Drainoni, 1999). In addition, for individuals with I/DD, health care interventions need to be integrated with the social supports available to the individual including family, school, work, and paid caretakers.

2.2. Health Care Integration

The development of the medical home concept during the past 40 years led, during the past decade, to a new understanding of the need for the integration of various health care and other supports—especially for persons with I/DD. Some of the impetus for integration of health care elements arose in the mental health field. It became clear that the lack of coordination among health care providers treating patients with psychiatric disorders hampered recovery (Dickerson et al., 2003; Horvitz-Lennon, Kilbourne, & Pincus, 2006).

However, as early as the mid-1990s, the importance of integrated care was being recognized. In a 1996 report on primary care, the Institute of Medicine (1996) highlighted the importance of integration in primary care as follows: “Primary care is 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.” (p. 31, emphasis added). This statement by the Institute of Medicine encompasses many, if not most, of the elements that underlie the medical home—care that is comprehensive and coordinated as well as continuous in the sense that there is an ongoing and sustained relationship between the health care practitioner and the patient.

The potential benefits to the I/DD population of such integration within a medical home are clear: (1) multiple services and supports received by individuals in this population are integrated into unified plans; (2) services are rendered accessible and provided in natural environments in community settings; and (3) services and supports are comprehensive including, for example, access to various health and mental health services, behavioral supports, specialty care, or other ancillary services such as rehabilitation supports and genetic screening.

Service integration is important if we are to include the health care of persons with I/DD in the larger American health care system—rather than having such care remain in “specialty” clinics or attached to small parts of other safety-net providers. In order to fully support people with I/DD living in community settings, a service model is needed that can survive and be replicated in the general health care marketplace. Because it draws on ideas prominent in general health care, the DD Health Home is flexible and can be replicated in diverse health care markets.

Before describing the DD Health Home in detail, however, it is important to understand something of the larger health care system in

America. As noted at the outset, that system is in flux. New ideas are being sought and developed to reform American health care; many of these new ideas are embodied in the Affordable Care Act. A brief overview of the law and an overview of health care funding approaches are provided as a prelude to presentation of the DD Health Home.

2.3. Overview of the Patient Protection and Affordable Care Act

Although quite complex, the Affordable Care Act highlights a number of important trends that will affect all health care reform efforts in America going forward. Signed into law on 23 March 2010 by President Obama, the law was originally challenged on several fronts by states, organizations, and individuals, although in upholding the law, the Supreme Court may have blunted many of these challenges. Regardless, these concerns are of less interest here; rather, more important in this context is the impact the novel ideas contained in the Act may have on American health care in general and persons with I/DD in particular. The Affordable Care Act includes many provisions, some of which became effective when the law was signed, and others that were deferred and either have already taken effect or are scheduled to take effect on dates stretching out to 2020.

In its entirety, the Affordable Care Act provides a blueprint for how health reform is likely to progress. For example, the Act includes important changes in the way health care is delivered and how reimbursement systems pay for it. It emphasizes health care outcomes as opposed to medical procedures and retrospective payment. The Act created an independent, nonprofit, patient-centered outcome research institute with the goal of shifting the focus from procedures to patient outcomes. Additionally, it created a council within the US Department of Health and Human Services focused on prevention and health promotion. Provisions such as these signal a shift in health care emphasis away from traditional approaches of simply treating diseases, toward prevention, health promotion, and improving health outcomes. In fact, beginning on 1 January 2015, the Affordable Care Act requires that payment for physicians' services be modified such that payment is made on the basis of quality of care, and not on the volume of patients and procedures.

The Affordable Care Act has brought to light the fact that much spending on health care in America may do little to actually improve the health of the nation's citizens. For example, health care dollars are often

wasted in a fragmented health care system as tests are repeated and information lost simply because records cannot be shared among physicians. With the threat of malpractice suits, many physicians practice defensive medicine, ordering needless tests and assessments which drive up costs.

The Affordable Care Act seeks to reverse these trends. By opening the door to novel approaches, the Act provides for the nurturing of new ideas on how health and health care are construed. It also seeks to stimulate new approaches toward coordinating care and improving quality. In this way, it will be a driver of innovative approaches to health care that focus on the triple aim. It is important that policymakers and service providers in the I/DD field assure that individuals with I/DD are not overlooked as health care reforms move forward. It is in this context of change that the DD Health Home has developed.

2.4. Health Care Funding

Although health care reform includes lofty goals, no health care model can be sustained if there is not a viable financial model underlying it. While the goal of primary care practitioners is to provide good health care, an important secondary goal is to generate sufficient income to support their practices. To fully understand the practice behavior of physicians, one must also consider their business interests and how they are paid. For example, under the fee-for-service model, physicians are paid a fee for each procedure or service rendered, generating more fees as the number of procedures or services increases. This payment method creates an obvious incentive for the practitioner to provide more care, even when the benefit of that care may be marginal.

On the patient side, the incentive to consume more services is not opposed by those who use health care because insurance, and perhaps the absence of co-pays and deductibles, insulate them from the costs of care. Furthermore, for persons with I/DD, health care services are often considered an entitlement because they are offered through the Medicaid and Medicare programs. In the past, however, there have not been effective cost controls in these programs. Therefore, as costs have increased, managed care options have been introduced into both Medicare and Medicaid. In fact, the majority of states now rely upon Medicaid managed care to provide services and manage costs for their Medicaid programs. Additionally, the mandatory enrollment in managed care of persons with I/DD who receive Medicaid benefits is rapidly expanding.

In order to survive, the DD Health Home described below requires a business model that simultaneously supports health promotion and reduces costs. But to understand the business model underlying the DD Health Home, it is necessary to understand current approaches to cost containment. Three broad approaches to cost containment will be briefly described: (1) approaches that relate to external management such as Health Maintenance Organizations (HMOs), (2) provider payment reforms including Accountable Care Organizations (ACOs), and (3) incentives to change consumer behavior.

2.4.1. External Management of Utilization

In 1973, Congress passed the Health Maintenance Organization Act. This Act encouraged the growth of HMOs, which were the first form of managed care. At first, it was thought that HMOs could control costs through "capitated" payment systems. In a capitated system, instead of being paid for each service, practitioners are paid a set amount each month for each of their patients for providing all of the care needed. At present, approximately 90% of insured Americans are enrolled in plans with some form of managed care, although the use of capitated payment systems in managed care is not as widespread as might be expected.

Furthermore, although HMOs are the predominant form of managed care, the term has now broadened to describe a variety of organizations. Managed care companies now include insurance companies, administrative services organizations, disease management organizations, and other health management companies. To manage costs, these organizations use a wide range of techniques including preauthorizations for care, concurrent review of proposed care, retrospective review of practice patterns, the use of formularies (lists of approved medications) to control pharmacy costs, and in-hospital discharge planning programs. Patients now commonly encounter medical procedures that cannot go forward, or prescriptions that cannot be filled, until the payer has approved them.

Over time, many health management organizations have blended care management concepts with utilization management activities. Unfortunately, the intent of traditional utilization management was solely to control costs, typically by restricting access to care in one way or another. Care management on the other hand, arose in the context of coordinating care to improve quality. Regardless, the term "managed care" has now come to signify a general philosophy of cost containment rather than any specific management approach.

Initially, the use of HMOs, at least in the public sector, was somewhat successful in containing rapidly rising health care costs by reducing unnecessary hospital use as well as the rates paid to practitioners for services. The result was that the health care industry became more efficient and also more competitive. However, despite the efforts of managed care organizations to control health care costs, costs began to rise again during the late 1990s. Additionally, public sentiment began to turn against managed care. In a poll by the Kaiser Family Foundation, a majority of those polled said they believed that managed care decreased the time doctors spent with patients, made it harder for people who are sick to see specialists, and had failed to produce significant health care savings (Kaiser Public Opinion Spotlight, 2006). In contrast, Mechanic (2001) argued that criticisms of HMOs should be tempered due to a general lack of understanding of how these companies actually work. Nonetheless, HMOs also detected the public sentiment and sought to offer less restrictive plans that were more flexible for consumers (Draper, Hurley, Lesser, & Strunk, 2002). Unfortunately, the falling public perception of managed care was also accompanied by growing *provider* resistance. Ironically, problems with providers may have been due to a gradual shift away from capitation as the primary means of reimbursement on the part of managed care organizations. Many plans increased the use of fee-for-service payment models, coupled with reduced rates, to improve their financial performance. However, the shift to fee-for-service and the weakening of rates unfortunately may have actually undermined the success of attempts to align the financial interests of providers and payers.

Ultimately, the long-term reliance upon managed care techniques will be determined by the willingness of HMOs and states to continue to work together. Already the relationship appears to be fraying. HMOs note that the profit margins in public programs such as Medicaid and Medicare are lower than those in commercial markets and argue that capitation payments do not reflect the true costs of care. On the other hand, states may feel that the costs of management are too high (Herring and Adams, 2010). Consider that when states pay premiums to HMO plans, the percentage of the premium that is actually spent on health care services, referred to as the health benefits ratio (HBR), averages only 80–90%. State officials may rightly wonder if the 10–20% spent on administrative expenses and profit could not be better spent on health care services for beneficiaries.

As a result, some states may want to move away from managed care and reconsider a single-payer approach. Vermont, for example, recently passed a single-payer health care bill and is seeking special approval from the federal

government to implement it by 2014. Under the Affordable Care Act, states will be permitted to enact single-payer systems beginning in 2017. Many Americans continue to see single-payer systems as a viable solution to coverage for all citizens. Vermont is likely the first of several states that will seek to implement single-payer systems under the Act.

2.4.2. Provider Payment Reform

Efforts to reform payment to providers have been directed at aligning the incentives of the provider with those of payers, which are government entities for Medicare and Medicaid. These efforts are characterized by attempts to eliminate the incentive of providers to increase service utilization and require that the practitioner assumes some degree of financial risk for managing the future health care costs of patients. For example, in fee-for-service models, a health care provider bills for each service delivered to a patient. In the future, however, providers will be asked to take more responsibility for the overall health of patients. Having providers shift their focus to the overall health of patients will likely be accomplished by capitating payments in *prospective* payment systems. That is, a health provider will be paid a specified amount for each patient which, when aggregated, will constitute a budget for the provider. If service utilization is below what is budgeted, the provider earns a profit; if utilization exceeds what was anticipated, the provider assumes a financial loss.

In small populations with substantial variability among members, such as in persons with I/DD, this risk may be too great to bear. Being able to bear risk through capitation payments depends on the ability to predict future health care use. Predicting health care use, however, may be particularly difficult for persons with disabilities, a fact that would provide a disincentive for providers to serve persons with I/DD. In the end, capitated systems favor larger providers because risk can be spread over a larger group.

Furthermore, the actuarial approaches used to predict future health care use and establish costs, such as relying on procedure codes (e.g. CPT or ICD-9 codes) or on past history, are often not especially accurate. As a result, risk capitation is associated with larger organizations and poses greater financial risk when applied to small providers (Cox, 2010). Therefore, going forward, actuarial uncertainty will favor larger organizations, whether they are provider or insurance based. Such uncertainty represents yet another argument for the inclusion of individuals with I/DD in larger health care systems.

Despite the problems in such prospective payment systems, efforts to reform medical payments have been rejuvenated in the Affordable Care Act through the inclusion of ACOs. An ACO is an organization that consists of a number of coordinated health care providers. Through the ACO, these providers agree to be accountable for the overall care, costs, and quality of services for a specified population of patients (such as Medicare patients). The idea is that with a coordinated treatment model, provider-led ACOs can use capitated payments to make practitioner reimbursement dependent on the quality of care and the overall reduction of excess utilization. Thus, by emphasizing primary care in a defined population of patients, experienced providers, organized in ACOs, are thought to be able to improve care while achieving cost savings (McClellan, McKethan, Lewis, Roski, & Fisher, 2010).

The defining qualities of ACOs support and reinforce elements of the medical home. Both promote integrated models of health care while at the same time addressing the triple aim of care identified by Berwick. Although early in its development, the ACO approach holds promise for providing a sustainable funding model for future medical homes serving persons with I/DD.

2.4.3. Changing Patient Behavior

A third way in which costs can be lowered is changing how patients use health care services by shifting part of the costs of care onto them. Requiring at least some payment from patients is called cost sharing. Forty years ago, beginning in 1971 and lasting until 1982, the RAND Corporation conducted the Health Insurance Experiment, which is the “only long-term, experimental study of cost sharing and its effect on service use, quality of care, and health.” (RAND Health, 2006, p. 1). The purpose of the research was to learn the effects of cost sharing or membership in an HMO on the use, appropriateness, and quality of care received.

This large-scale randomized experiment included more than 7700 individuals under the age of 65 years, chosen from six sites across the United States. The study examined the behavior of patients by assigning them to one of five experimental conditions. One condition offered free health care while three others included cost sharing by patients at three different levels—25, 50, or 95%. For poorer patients, costs in these conditions were adjusted based on income to 5, 10, or 15% of income, with a cap on total out-of-pocket expenses. The fifth condition enrolled patients in a free, nonprofit HMO-style group cooperative plan. Results showed that cost

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sharing did not significantly affect the quality of care received by the study participants, although it reduced the use of nearly all health care services. However, the reductions in health care use did not distinguish between the consumption of effective or less-effective care—both types of care were reduced about the same. Quality of care was problematic across all conditions and also was not differentially affected by cost-sharing conditions. Furthermore, despite the fact that health outcomes were not significantly different than in other groups, patients assigned to the HMO condition were less satisfied with their care. The authors concluded, in general, that cost sharing reduced costs but did not have adverse effects on the general health of participants. Reductions in costs through cost-sharing plans, without associated loss of quality, have led to calls for an expanded role for cost-sharing payment models.

However, based on the general lack of consumer enthusiasm and the lack of additional empirical support, advocates concluded that cost sharing, even if it were possible under current Medicaid rules, should not be applied to Medicaid beneficiaries, particularly those in Aged, Blind, and Disabled programs. For now, substantial cost sharing in public programs does not seem to be on the horizon although it could find its way into the Medicaid and Medicare programs after the implementation of external management and payment reform measures. Many states already impose co-pays on some Medicaid beneficiaries for certain services (such as emergency room use or some pharmaceuticals). Shifting a greater share of costs and responsibility to Medicaid beneficiaries would increase the value of the medical home as it will create financial incentives for consumers to seek information that can not only improve health but also reduce personal expenditures as well.



3. THE DD HEALTH HOME MODEL

3.1. Description of the Model

These health care and reimbursement reform ideas may seem disparate and confusing at first. However, it is possible to organize these ideas into cohesive health care models that can benefit persons with I/DD. The DD Health Home is such a model. The DD Health Home provides comprehensive primary health care services in normalized, community-based office settings that go beyond typical primary care to incorporate care coordination and elements of specialty care. Aspects of the model have been previously described in the literature under different names (Kastner & Walsh, 2006;

Ziring et al., 1988). The name of the model—initially the “Morristown Model” then the “DDHA Model” and now the “DD Health Home”—has evolved as organizational affiliations and locations have changed over the years.

The model employs nurse practitioners in conjunction with physicians, typically internal medicine physicians, who provide multiple services within a medical home primary care practice. Additionally, primary care nurse practitioners serve as health care coordinators and are cross-trained in primary mental health care for patients with I/DD as well as in basic neurological services (e.g. seizure management). Patient care is managed within the context of a set of copyrighted practice guidelines specifically developed for persons with developmental disabilities.

A patient is initially seen by a nurse practitioner who provides most care. When more care is needed, a patient will be referred to a consulting physician in the DD Health Home office. If the person needs mental health care, this is arranged and the patient is seen for mental health services, also in the DD Health Home office. Once stabilized, the patient will be followed by a nurse practitioner. Nurse practitioners are on call enabling patients to reach someone in the practice at all times. Through the use of electronic medical records, each patient’s medical record is available to all nurse practitioners who take call—regardless of which DD Health Home office the patient is from.

Nurse practitioners also carry out a number of other care-coordination functions designed to manage patients efficiently as possible. Some of these functions are not unlike what parents do for children or adult children do for their aging parents—scheduling appointments, arranging for laboratory testing or medical procedures, and assisting in managing insurance issues. Other tasks are related to medical care, such as clearing patients for surgeries, following up emergency room visits, renewing prescriptions, and managing medical documentation.

The DD Health Home model has shown promise in providing a replicable, specialized I/DD medical home for individuals living in community settings. The model avoids many of the pitfalls of health care systems in the past and incorporates many of the most advanced ideas in the field. Although the DD Health Home offices appear as typical primary care practice offices, they are specialized for treatment of individuals with I/DD. For example, the offices are accessible (e.g. they have ramps and ample handicapped parking) and are equipped with motorized examination tables, seated weight scales, and other equipment needed to provide care to patients with

disabilities. Although the structure of the DD Health Home offices is adapted in many ways, offices are little different than a typical doctor's office. Nonetheless, the medical encounter processes and the practitioner services *are* remarkably different. In the DD Health Home, the typical primary care office visit has been wholly re-engineered to meet the needs of individuals with I/DD (Berenson et al., 2008; Casalino, 2010; Friedberg, Hussey, & Schneider, 2010; Kastner, 2004; Philips, O'Chesky, & Kastner, 1995).

Although many of the typical services of a primary health care setting are provided (see top part of Table 1), they are specialized for the I/DD population. A defining element of the DD Health Home is health care coordination—a function carried out by the nurse practitioner who also delivers primary care. Care-coordination functions include regular telephone contact with patients, ongoing assessment of treatment compliance, making and coordinating routine appointments with health care providers, follow-up clearance for hospitalizations and emergency room visits, updating electronic medical records, and fulfilling documentation requests.

The DD Health Home model goes beyond typical primary care services by *integrating* mental health services and specialty medical care including

Table 1 DD Health Home Service Areas

Area	Service
Primary care	Annual physical examinations
	Acute care office visits (diagnostic assessment and treatment)
	Ongoing care for chronic conditions
	Care coordination
	Medication management
	Preadmission screenings
	Postemergency room and posthospitalization follow-up visits
	Health screenings (e.g. breast cancer)
	Disease prevention (e.g. immunizations)
	Health promotion activities (e.g. nutritional counseling)
	Blood draws
	Tuberculosis testing
	Immunizations
	Camp physicals
	Service provider documentation
Specialty care	Mental health diagnostic assessment and treatment
	Psychiatric medication management
	Primary neurology (seizure management)
	Gynecological examinations

services such as seizure management and gynecological examinations (bottom of Table 1).

The integration of primary care and selected specialty care practices is one of the strengths of the DD Health Home in that many individuals with I/DD have both mental health and neurological needs. The integration of specialty care is especially important for this population because typical treatment approaches can interact across areas. Consider the case of a patient who exhibits both psychiatric illness (bipolar disorder) and a neurological condition (seizures). This person's primary care provider might prescribe an antiepileptic mood stabilizer (valproic acid) which may affect the individual's psychiatric illness as well as the seizures. If this individual's caretakers also seek treatment from both a neurologist and a psychiatrist, the treatment may be adversely affected when these two specialists attempt to manage the medication differently.

In such a case, a neurologist and a psychiatrist are both likely to use this class of medication. However, they would have different treatment goals and would consider different dose ranges of the medication. The two specialists are also apt to use different risk/benefit ratios and different drug withdrawal criteria. Although the neurologist may be able to achieve seizure control with, for example, a serum valproic acid level of 50 mcg/dl, this level may be insufficient to achieve remission of mania. In this case, the neurologist would likely want to maintain the level of medicine while the psychiatrist may want to increase it. A further complicating issue, of course, is that neither may be able to effectively communicate with the primary care provider.

Such a lack of coordination could easily result in deleterious effects for the patient. In this example, there could be dose-related side effects of valproic acid including hair loss, weight gain, ankle swelling, thrombocytopenia (a relative decrease in platelets in the blood), and other concerns. While doses that produce some or all of these side effects may be an acceptable risk to the psychiatrist if the patient is manic and suicidal, they may not appear acceptable to the neurologist if seizures have been brought under control. Problems in the care of such a patient may be exacerbated if the various practitioners cannot easily communicate or coordinate their care. The end result is that the patient may have multiple treating physicians working at cross-purposes who are relying on the same medication.

A problem like this is not possible in the DD Health Home because the care is integrated within a single medical practice that involves the primary care practitioner and includes care in both specialty areas. Patients who are diagnosed with multiple conditions, including psychiatric and neurological

diagnoses, receive coordinated care, monitoring for medication interactions and side effects as well as regular review of the effectiveness of all relevant treatments as part of their routine care. Thus, I/DD patients who present with multiple conditions often receive appropriate care without the need to coordinate two or more completely independent practitioners.

The core of the DD Health Home clinical practice model is a team approach that relies on an interdisciplinary relationship between physicians and nurse practitioners. Firmly entrenched in the model is the principle that nurse practitioners can serve multiple roles as effective team leaders, clinicians, and care coordinators—a view which finds currency in recommendations for transforming the larger health care system (Bauer, 2010; Bodenheimer & Pham, 2010; Naylor & Kurtzman, 2010). In the model, nurse practitioners take the lead and provide primary care as well as mental health and basic neurological care (i.e. seizure management); however, they also have access to physician specialists who provide support and enhance their practice patterns.

Because the DD Health Home is an expanded primary care model, long-term relationships are developed between patients and practitioners in the medical office sites. In this way, continuity is built into the model based on the limited size of the practices and the caseloads of individual practitioners. Experience and patient surveys have shown that patients become close to the physicians and nurse practitioners and value the continuity and personalized care available in the model. This broader sweep of care and its coordinated management are designed to achieve the triple aim of better care, better health, and lower costs.

A few examples will illustrate. A profoundly disabled young man who had lived at home with his mother and grandmother and according to them had “never been to a doctor” presented in a DD Health Home office. As part of the enrollment process for a day program, he needed a simple Mantoux test for tuberculosis (TB). The lack of this test had prevented his day program enrollment for more than a year. The problem was that he was fearful of the intradermal injection required, and became aggressive toward health care workers who approached him. To counter this behavior, the young man was scheduled to come to the office repeatedly over the course of a month. During these visits, he had coffee with staff members and was allowed to freely explore all the rooms. In addition, simple procedures such as taking his temperature and taking his blood pressure were carried out to desensitize him to medical procedures. On his fourth visit, the TB test was successfully administered and on his sixth visit, a successful blood draw was

accomplished. The nurse practitioner immediately forwarded the test results to the day program and the young man was enrolled—he also became a regular patient of the DD Health Home. Nurse practitioners similarly desensitized a young woman who reacted to physical examination by screaming and scratching practitioners and who had previously been dismissed from several physicians practices.

Many patients with poor access to care or poor care have presented in the DD Health Home offices. More than once, patients were directly moved to hospital emergency departments via 9-1-1 because of dangerous cardiac, pulmonary, or similar problems. Physical abuse and neglect of patients by caretakers and residential staff have also been discovered, exposed, and rectified. In all these cases, coordination and communication with other agencies, regular case managers, or government officials are vital to good outcomes.

Once patients come into care in the DD Health Home, their care becomes organized and efficient. The availability of care and on-call contact with practitioners permits the rerouting to the DD Health Home what often would have been unnecessary and wasteful emergency department visits or hospital admissions.

The beneficial aspects of the DD Health Home model have led to recognition in the field. For example, the model was deemed an especially creative program in the US Surgeon General's report (US Public Health Service, 2002) which cited the model as "... an effective way of providing an array of managed care services to individuals with MR relying on Medicaid reimbursements. Success is also related to developing the talents of staff and being flexible in the face of market changes ... (to) add value to services provided, to leverage funds effectively, to use capitation effectively and to develop a good business plan." (p. A-6, 7). In addition, researchers at the University of Massachusetts Medical School have included the model as a "promising practice" in their nationwide study of six models of Medicaid managed care developed for the Supplemental Security Income (SSI) population (Beamon, Stewart-Pagan, & O'Connor, 2004). Additionally, the federal Center for Medicare and Medicaid Innovation has chosen to provide funds to the DD Health Home for a 3-year demonstration program in three states.

3.2. Re-engineering of Care Practices

The re-engineering of care practices in the DD Health Home model was first described by Kastner and his colleagues beginning in the late 1980s and

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1990s (Criscione, Kastner, Walsh, & Nathanson, 1993; Criscione et al., 1995; Kastner & Walsh, 1999; Philips et al., 1995; Ziring et al., 1988). This work delineated the roles and responsibilities of the team members and ascribed to nurse practitioners an independent practice role as well as a care-coordination role. Nurse practitioners were seen as working independently although, at the same time, collaboratively, with physicians and other personnel serving the patient (Philips et al., 1995).

As noted, to achieve improvements in overall health care, nurse practitioners in the DD Health Home are cross-trained in basic mental health and neurological care which serves to integrate these specialties with primary care treatments. This cross-training is vitally important to both the quality of care and the cost savings because mental health issues and seizures are common comorbidities in this population. When these components are not integrated, patients are typically sent to independent specialty practitioners with, as described above, the potential for different practitioners to work at cross-purposes. For reasons such as these, and because specialists are often difficult to reach, the model also simplifies communication through its 24/7 on-call access to nurse practitioners.

In the DD Health Home, the primary care provider occupies a central place—primary care is considered to be the first point of contact in all health care encounters. In this way, the use of emergency departments and hospital admissions are reduced or avoided. In the model, *primary care* has been redefined and re-engineered to incorporate more than what typically passes for primary care in other systems. The integration of primary care and selected specialty services maintains the client as the focal point of care (e.g. Berenson et al., 2008).

Additionally, such integration is directly related to the nature of this population because, as a group, persons with I/DD have higher rates than the general population of comorbid conditions and of sensory and other physical disabilities. Associated conditions such as sensory deficits, speech problems, ambulation and gait disabilities, metabolic disorders, and higher rates of mental health and psychiatric disorders complicate the care of this group. Patients with I/DD also exhibit predictable rates of complex behavioral problems arising separately or in conjunction with mental health problems, adaptive skill deficits, or environmental factors. Because of these characteristics of I/DD patients, nurse practitioners take the lead and provide primary care as well as mental health and basic neurological care (i.e. seizure management). At the same time, however, they have access to internal medicine physicians who support and enhance their individual practice patterns.

Because patients with I/DD as a group use more health care, they have more office visits per year than nondisabled patients. To account for this, nurse practitioner caseloads in the model are maintained between 250 and 300 patients giving rise to between 1000 and 1500 patient visits per year compared to perhaps twice that number in general primary care practices. Because shorter office visits are associated with reduced quality of care and decreased patient satisfaction (e.g. Halfon, Stevens, Larson, & Olson, 2011), office visits in the model are designed to be lengthy and comprehensive often lasting between 30 and 60 min. Because of their smaller caseloads, nurse practitioners each handle between 30 and 40 office visits per week. This, in turn, provides approximately 10–15 hours per week for nurse practitioners to devote to care-coordination functions (Criscione et al., 1995; Kastner, 1999) which improves the quality of care. Finally, because of reduced caseloads, there is less pressure on the daily office schedule and patients can typically be seen for primary care visits on either the same day or the next day after an office is contacted, and within a week for mental health visits. Additionally, because fewer patients are seen on any given day, the average waiting time in DD Health Home offices has been found to be less than 7 minutes (Walsh, 2007).

The expanded role of nurse practitioners allows physicians, as either primary care providers or specialists, to focus on the goal of advancing the health of an entire patient panel (cf. Casalino, 2010; Friedberg et al., 2010; Kilo & Wasson, 2010) while the bulk of services to individual patients are provided by nurse practitioners. Therefore, a primary care consultant physician attends to each DD Health Home office for approximately one-half day per week seeing patients referred by the nurse practitioners (or, more likely, in conjunction with them), reviewing treatments, and reviewing cases with an eye to improving the health of all patients. In this way, the physician's role is to support the nurse practitioners in managing the health care needs of their patients. They do this by helping to evaluate new patients, solve complex diagnostic issues, interpret complicated treatment data, and follow up with those patients whose care warrants the services of a physician.

Additionally, the inclusion of routine health care coordination in the model, provided by primary care nurse practitioners, enhances any existing case managers already in the system. Patients with I/DD often have more than one case manager, caseworker, or social worker located in various state programs or educational settings. A common problem is the lack of coordination among various systems providing services and supports to a person. In the present model, nurse practitioners become aware of the necessity of

linking with all available case managers working with a patient and, if necessary, they can provide a coordinating function among them in order to maximize positive health outcomes.

Nurse practitioners in the DD Health Home are able to tailor care to individual patients and efficiently arrange resources, including preventive services, hospital admissions/discharges, home care, inpatient and outpatient surgery, medical equipment, and pharmacy services. Through regular telephone contact with patients, nurse practitioners are able to identify atypical needs, avoid unnecessary utilization, ensure compliance with medications and other recommendations, encourage improved diet and self-care, and coordinate family and community resources. In short, the positive effects and outcomes of primary care are enhanced because the treatment interventions for the patient in the DD Health Home are directly structured around the person's needs.

3.3. Reimbursement: Notes on Funding the Model

Transforming care practices requires a change in how the DD Health Home is reimbursed for services. In this regard, it is important to understand whether the I/DD population is considered to be part of the larger health care population (Kastner & Walsh, 2006). Patients with I/DD can be included in a larger system (which is referred to as *carved in*) or they can be part of a payment system, with potentially higher rates, that is established separately from the system in which the general population is funded (referred to as *carved out*).

There are benefits and drawback in both approaches. For example, when the I/DD population is carved out of general payment structures, it may be easier to provide the highly specialized services needed by this group. However, because the services are highly specialized and the providers bear no risk, such services may become quite costly and yet remain protected from the forces that serve to lower costs in larger systems.

From the foregoing discussion, it is clear that the major goal of the DD Health Home is to have practitioners focus on improving the health of patients rather than on simply generating income under a fee-for-service arrangement. Because many patients with I/DD use more health care services than persons in the general population, the DD Health Home is exposed to "adverse selection"—a term given to the phenomenon that occurs when a health care provider attracts patients who are sicker or require more services than others.

To deal with the problem of adverse selection, *risk adjustment* processes need to be used to adjust capitation payments based on the severity of the person's illness. In fact, the Affordable Care Act requires that risk adjustment programs begin to operate by January 2014 to address such adverse selection and stabilize premiums (O'Sullivan, 2012). Although prospective forms of payment such as capitation will best support replications of the DD Health Home, or similar projects in the future, actuarial uncertainty will compel such projects to serve the largest number of patients possible. It is conceivable that a capitated I/DD medical home provider would serve a county, a multicounty region, or even (in a small state) a statewide clientele. As a result, such health home projects may need to consider acquisition, mergers, or other activities to achieve scale.

As currently constituted, the ACO contracting platform represents an opportunity for organizations to contract directly with Medicare and, subsequently, perhaps other payers. At present, there are no I/DD medical home projects able to serve the 5000 Medicare beneficiaries required for an organization to qualify as an ACO. However, it is possible in the future that I/DD medical home ACOs, based on the model described here, could emerge as a viable entity. If so, such an organization could attempt to contract with a State Medicaid agency directly or affiliate with long-term care providers. This would allow the I/DD medical home to also incorporate the provision of long-term care supports under the Medicaid Home and Community-Based Services (HCBS) waiver program.

In any case, I/DD medical home projects will need to be attentive to revenue, operating costs, the costs of care, and cost savings. In addition to meeting the triple aim of health care, the success of the model depends on its ability to demonstrate that it can simultaneously satisfy multiple stakeholders—patients, providers, and payers.



4. OUTCOMES AND EVIDENCE FOR EFFICACY OF THE MODEL

Because the DD Health Home has been operating, albeit under different names, for over 25 years, there has been time to amass a body of research that evaluates the model. During this time, various study projects have supported the conclusion that the model routinely addresses elements of good health care as embodied in the triple aim—improving the experience of care, improving health, and reducing costs (Berwick et al., 2008). Studies that address this triple aim conducted within the DD Health Home model fall

into three broad categories: (1) early clinical studies that supported the re-engineering of the medical encounter as well as the development of clinical guidelines; (2) patient satisfaction and quality of care studies, and (3) utilization studies showing the effects of the model on outcomes such as costs and hospital and emergency room use. The results of utilization studies are becoming especially important during a period in which American health care policymakers are considering how to reconfigure the nation's health care system and practitioners are addressing improvements in patient care. Each category of studies will be described, in turn, and evaluated against the triple aim outlined by Berwick and his colleagues.

4.1. Early Clinical Studies

From a scientific perspective, one of the benefits of the specialized clinical practice in the DD Health Home is that it provides a concentration of patients with I/DD for clinical and applied studies. Over the years, the model has produced many published reports that, taken together, speak to the goals of improving the clinical care of patients with I/DD as well as contributing to the knowledge needed for evidence-based practices. There have been efforts to create practice guidelines in diverse areas of care for disabled persons such as primary care (Kastner, 2004; Sullivan et al., 2011), screening and diagnosis in autism (Filipek et al., 2000), nutritional services (American Dietetic Association, 2004), and cytogenetic evaluation (Shaffer, 2005). But until a quarter century ago, there were few resources upon which practitioners could rely. It was this paucity of clinical research findings that, in part, prompted the applied and clinical studies noted below that were carried out in the DD Health Home.

Over the past 25 years, a number of clinical topics have been identified and studied. These include the following:

- Predental prophylaxis screening for heart disease in persons with Down syndrome (Barrett, Friedman, & Kastner, 1988);
- Screening for thyroid disease in persons with Down syndrome (Friedman, Kastner, Pond, & O'Brien, 1989);
- Measuring effectiveness of valproic acid in the treatment of children with developmental disabilities and mood disorders (Kastner & Friedman, 1992; Kastner, Friedman, Plummer, Ruiz, & Henning, 1990; Kastner, Walsh, & Finesmith, 1993);
- Improving immunization rates against pertussis in children born prematurely (Kastner, Ruiz, & Nathanson, 1991);

- Recognizing adverse effects of carbamazepine (Friedman, Kastner, Plummer, Ruiz, & Henning, 1992; Kastner, Friedman, & Pond, 1992);
- Evaluating the effectiveness of gastrostomy in preventing aspiration pneumonia (Kastner, 1992; Kastner & Walsh, 1995a);
- Tube feeding and mortality (Strauss, Kastner, Ashwal, & White, 1997);
- Guidance and recommendations on managing human immunodeficiency virus (Kastner, DeLotto, & Scagnelli, 1990; Nathanson, Kastner, & Marchetti, 1992);
- Practices and outcomes associated with psychotropic medication treatment (Kalachnik et al., 1997; Kastner & Walsh, 1994; Kastner, Walsh, & Fraser, 2001);
- Clinical practices associated with risperidone (Kastner, 2005; Kastner & Walsh, 2004);
- Highlighting preventive services (Kastner, Walsh, & Criscione, 1996); and
- Primary care practitioner guidance for behavioral problems (Kastner & Walsh, 1995b, 2011).

Additionally, following many I/DD patients over time has suggested that, as a group, mortality rates may be increased in certain community-based settings because dispersed health care practitioners may not be properly monitoring these patients (Kastner, Nathanson, & Friedman, 1993; Strauss & Kastner, 1996; Strauss, Kastner, & Shavelle, 1998). Furthermore, studies such as these have led into policy areas as well, including health care for children with special health care needs (Kastner, 1999, 2004; Blum, Hirsch, Kastner, Quint, & Sandler, 2002).

By almost any standard, the number and the scope of these publications are impressive, especially so as they have arisen from a primary care practice. Taken together, they speak to the types of problems and the need for clinical knowledge practitioners encounter in providing primary care to patients with I/DD. Most of these clinical studies came about because of problems clinicians in the program faced with their patients. Many of them have to do with mental health interventions and reinforce the need to integrate psychiatric care with primary care for this population.

A related benefit of this level of attention is that the DD Health Home has given rise to, and has incorporated into practice, a set of specialized practice guidelines designed specifically for delivering primary care to persons with I/DD. This set of clinical practice guidelines serves as a basis for the specialized primary care provided in the DD Health Home. These

practice guidelines address the specific clinical care issues of a host of medical syndromes that often affect patients with I/DD such as gastrointestinal disorders, tardive dyskinesia, mood disorders, feeding disorders, and patient evaluation and assessment issues.

What is more important is that the operation of this model over the past 25 years has given rise to a knowledge base, most of it published, that provides a foundation of clinical knowledge in the provision of quality health care for persons with I/DD. That is, this knowledge helps to inform routine primary care delivery, but has also had a salutary effect on the redesign of the practice setting (Berenson et al., 2008; Bodenheimer & Pham, 2010). Thus, as clinical findings were studied and conclusions were drawn, relevant changes in practice were inculcated into the model. In this way, this body of work clearly addresses the need of health care systems to “improve the health of populations” as articulated by Berwick and his colleagues (2008) on the triple aim of health care systems.

4.2. Patient Satisfaction and Quality of Care

Patient satisfaction and quality of care have long been important components of primary care practices (Daley, Gertman, & Delbanco, 1988; Walsh & Kastner, 1999) and have remained valued health care outcomes (Browne, Roseman, Shaller & Edgman-Levitan, 2010; Safran, 2003). Over the past two decades, the quality of health care has received extensive attention in the research literature. For example, a search of the Medline database between 1996 and the end of April 2012 using the search term “quality of health care” returned nearly 33,000 items. To assess patient satisfaction and care quality within the DD Health Home, a number of patient surveys were conducted using a carefully designed survey form that addressed critical domains of care.

At the time these efforts were initiated, there were few guideposts and no assessment instruments for the quality of primary care or patient satisfaction in this population. Therefore, a survey form was developed specifically for use in the multiple offices that shared the model. At that time, interest in measuring the overall quality of life in persons with I/DD was also escalating (Schalock, 1990; Schalock, Keith, Hoffman, & Karan, 1989). Unfortunately, this interest did not generally extend to health care quality measures. For example, Hughes, Hwang, Kim, Eisenman, and Killian (1995) in their extensive review of research published between 1970 and 1993 identified 1243 specific quality measures which they classified into 15 dimensions. The

dimension most closely associated with health care was Physical and Material Well Being containing nine items, only seven of which were in the physical health component (e.g. weight, blood pressure, and physical development). Thus, less than 1% of all these quality measures could be considered, in some way, to be related to health or health care.

Because of the lack of existing tools, guidance for the development of a health care quality and satisfaction survey was taken from the general health care literature at the time. A self-report survey form was developed that included items in four health-related domains: access (nine items), quality (six items), satisfaction (five items), and health status (six items). These domains were similar to those that have been identified as being important to primary care by John Ware and his colleagues (e.g. Safran et al., 1998). The specific domain to which survey items belonged was not apparent to the respondents. Items asked about accessing services, making appointments, working with office staff, the quality of care, privacy, interactions with practitioners, and general satisfaction with the offices, health care personnel, and care practices. In addition, the survey form included self-reported health outcomes and health status items to gauge perceived health improvement and normal activity levels of the person. In addition, the form provided space for individual written comments.

This patient quality and satisfaction survey form was administered in the primary care offices of the DD Health Home seven times beginning in 1995 (in 1995, 1998, 1999, 2004, 2005, 2006, and 2007) based on availability of resources to manage data collection. Results have been quite similar from year to year and, therefore, results from the 2007 administration of the survey are reported here (Walsh, 2007).

In that year, 179 survey forms were collected from six different primary care offices across New Jersey functioning as DD Health Homes. Patients for whom surveys were obtained ranged in age from 16 to 87 years. Surveys were collected from all patients who had medical appointments during a specified time period. Forms were completed at the end of routine office visits unless the patient or the patient's caregiver declined (which rarely occurred). Six of the survey forms (3.4%) were completed by patients with I/DD independently while the remaining 173 (96.6%) were completed by proxy respondents, typically caregivers or family members. Anecdotal observations suggest that many survey forms were completed in concert with the patient. Because respondents were given the option to complete the surveys without providing identifying information, the identity of the proxy respondents was known for only 125 surveys. Twenty (16%) were

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parents, three (2.4%) were siblings, 100 (80%) were staff or paid caregivers, and two (1.6%) were "other" (a therapist and a state caseworker). Of the 89 staff or paid caregivers who identified their position, 69 (77.5%) were at the direct care level and the remaining 20 (22.5%) were supervisory-level staff members.

Results from the survey suggested that the clinical services offered within the DD Health Home are highly valued by respondents. With regard to access to services, 99% of respondents reported that they were able to schedule appointments without delay and 97% agreed that phone calls to the offices were handled efficiently and effectively. As noted earlier, the average waiting room time was 6.9 min [standard deviation (SD) = 7.4]. Over 90% of respondents rated as either "very good" or "excellent" the ease of driving to the offices (95%), parking at the offices (91%), and aspects of the physical access to the waiting/exam rooms (97%).

On the quality of care received, respondents "agreed" or "strongly agreed" over 90% of the time with statements about (1) the quality of care on the day of the survey visit (95%); (2) questions being fully answered and necessary information being provided (99%); and (3) that they experienced consistency and continuity in who provided their care (98%). Furthermore, over 98% of respondents agreed or strongly agreed that office visits were long enough, that the primary care practitioner listened to concerns, and that medical staff members were respectful to them. Positive ratings were also found for clerical staff with over 99% of respondents agreeing or strongly agreeing with statements that the clerical staff members were knowledgeable, courteous, and efficient. Twenty-four percent of the respondents rated the comfort of the waiting rooms good while 74% rated them as excellent and, once again, 99% of respondents agreed or strongly agreed that sufficient privacy was afforded during the health care visit.

In regard to the health status of the patients surveyed, 90% of respondents agreed or strongly agreed that the health of the person had improved during the year and 93% reported that the DD Health Home helped to keep them healthy. Supporting this finding of better self-reported health status, were reports that 88% of the patients surveyed continued to participate in day activities outside their home; 78% reported independence in walking, with the remainder reporting either the partial ambulation abilities (10%) or the inability to walk independently (13%).

On this survey, optional written comments were provided on 88 survey forms (49%) with comments being overwhelmingly positive. For example, a residential program director added this comment to a survey form:

I have been coming to this office for medical treatment for my clients ... for the past 5 years. All concerns and issues are always addressed promptly (and) all consumers appear to be happy as well.

A group home nurse wrote:

We are very pleased with the efficiency, accessibility and continuity of care we receive here. Office staff are efficient and professional. It is easy to get an appointment and it is a pleasant and enjoyable office to visit.

Although positive, such comments represent qualitative data and, as such, cannot be used in isolation to draw general conclusions. Nonetheless, they are often instructive in understanding the motivation behind the survey response patterns that were found. Therefore, a basic categorization of all comments was undertaken consistent with qualitative data analysis methods. Seven thematic categories that had been developed in past surveys were used to categorize each of the written comments included on the survey forms. The seven "qualitative" themes are shown below:

- (1) Staff characteristics: Positive comments related to "people," "staff," "office staff," "doctors and nurses," and/or their personalities and interaction styles.
- (2) Service structure: Positive comments related to space, cleanliness, waiting room, parking areas, exam room, and equipment, so-called structural elements of the office.
- (3) Service processes: Positive comments related to "processes" such as phone calls, prescription refills, appointments, emergencies, questions answered, forms sent, and similar office-based processes.
- (4) System issues: Positive comments with respect to any "system" elements such as managed care, the health home approach, or the insurance or payment systems.
- (5) Service quality: Positive comments with respect to clinical care or "services and treatments."
- (6) Other positive: Other positive comments that do not fit into the above themes.
- (7) Negative: Any and all negative comments.

The results of the categorization of the comments into these thematic categories are shown in Table 2. The total number of comments in the table sum to more than the overall number of surveys with comments because comments could be coded for multiple themes.

It is noteworthy that there were only 12 negative comments (theme #7), especially given that the request for comments on the survey form might be

Table 2 Written comment thematic coding results

Theme codes	Theme code designations	No. of "mentions"	Total "themes" (%)
1	Staff characteristics	35	28%
2	Service structure	6	5%
3	Service processes	11	9%
4	System issues	2	2%
5	Service quality	19	15%
6	Other positive	46	32%
7	Negative	12	10%
	Total	131	101%*

* Exceeds 100% due to rounding.

expected to produce negative comments because the instructions asked respondents to note what they *like* and what they *don't like* about their health care services. Five comments included both "likes" and "dislikes" and all of these were included under theme #7. The negative comments identified under this theme typically referred to areas other than health care such as waiting room concerns (e.g. wanting a television in the waiting room, or requesting a better magazine selection) or concerns about parking.

As shown in Table 2, the bulk of the comments (75%) were categorized into only three thematic areas: (1) positive comments about staff members (35 comments), (2) positive comments about the quality of services (19 comments), and (3) other general or nonspecific positive comments (46 comments).

Taken together, the survey findings and comments reveal that the array of primary care services and the manner in which they are delivered are highly valued. However, these findings are not necessarily surprising in terms of reports in the literature showing that health care consumers prefer easy access to services, longer clinical visits, and more communication from practitioners (Browne et al., 2010; Liptak et al., 2006; Lown, Rosen, & Marttila, 2011), elements that have been specifically included in the DD Health Home.

Of importance here is that these findings on satisfaction clearly address another of the elements of Berwick's triple aim for health care, namely that the "experience of health care" be improved (Berwick et al., 2008). These results mirror those from prior years and show that patients and/or their proxies are satisfied with their care experiences and believe that they enjoy better health because of them.

4.3. Utilization Studies

Thus far, the analyses of the performance of the DD Health Home have paralleled two of the three elements of the triple aim of health care. The early clinical studies of the DD Health Home model addressed the first of these aims—that is, they provided information useful in improving the health care of this population. The second thrust of work carried out in the DD Health Home, assessing patient satisfaction and quality, addressed the second aim—improving the experience of care. The final aim—reducing the per capita cost of care for populations—is directly relevant to the various utilization and cost analyses carried out with respect to the DD Health Home over the years.

4.3.1. Early Utilization Studies

When the DD Health Home first began to operate, it was clear that the most resource-intensive element of the model, care coordination, would need to be examined to determine the extent to which it could reduce utilization of more expensive forms of care (such as hospital admissions) thereby creating efficiencies in the model. At the time that the model began, in a single hospital in northern New Jersey, the lengths of hospital stays were longer than they are today because there were fewer forces to impose downward control on hospital admissions and to prompt timely discharge of patients. Although the diagnosis-related group (DRG) system was in place, managed care had not yet taken root in the region in which the center operated.

The DRG system was an early prospective payment system designed to control costs of hospitalizations and serve as a replacement for cost-based reimbursement. The DRG system classified hospital admissions into categories, or diagnostic-related groups, and provided payment for appropriate lengths of hospital stays. What little research was available at the time (e.g. Birenbaum, Guyot, & Cohen, 1990) pointed to longer hospital stays for people then considered to have mental retardation. These longer hospital stays would have been considered outliers in the DRG system and would have reduced revenue to the hospital. In fact, at the time, community-based physicians sometimes admitted patients with intellectual disabilities into the hospital to have them undergo evaluation, assessment, and laboratory tests and, perhaps, to avoid office appointments. Additionally, there were cases in which hospital stays grew inordinately long because of problems in discharging some of these patients back into community settings. All of these factors increased the costs of hospital care for patients with I/DD.

It was hypothesized that the care-coordination component of the DD Health Home model would result in more efficient management of patients overall, including while they were in the hospital, and in this way reduce hospital utilization to produce a cost savings. It was this hypothesis that the research program initially set out to test. Three studies were published in the 1990s that are particularly relevant to this question—Criscione et al. (1993, 1995) and Walsh, Kastner, and Criscione (1997).

In the first study (Criscione et al., 1993), patients with I/DD who had been admitted to a hospital during a single year were identified and divided into two groups—one group was from the DD Health Home and had nurse practitioners serving as care coordinators (the care-coordination group) and the second group consisted of admissions made by community physicians without care coordinators (the usual-care group). Individuals in the care-coordination group had 22.7% shorter hospital stays, just under two fewer days on average, than did the usual-care group. When length of hospital stay was adjusted for case mix using the DRG coding system, the difference increased to more than 3 days ($p < 0.05$) (Criscione et al., 1993).

Because patients in this population often have multiple hospital admissions in a given year, this study also examined the number of inpatient admissions during the year and found that the average number of admissions was significantly higher in the usual-care group (mean = 1.6, SD = 0.99) than in the care-coordination group (mean = 1.2, SD = 0.45) ($p < 0.02$). In the care-coordination group, only 13.9% of the patients were admitted more than once during the year compared to 34% of the usual-care group. These findings supported the hypothesis that care coordination had an effect on hospital utilization and was a valuable addition to the array of primary care services in the model. The next study in the series (Criscione et al., 1995) sought to replicate these findings and extend them.

This study retrospectively identified all hospital admissions of individuals with developmental disabilities over a 3-year period and again divided them into a usual-care group and a care-coordination group. Hospital utilization (length of stay) and costs (hospital charges) were compared. Once again, comparison of the length of hospital stays showed the effects of care coordination. The average length of stay in the group of patients who received care coordination through the DD Health Home was 36.6% shorter than the length of stay of individuals without care coordination (the usual-care group). When the length of stay measure was adjusted for the *case mix* of the groups (i.e. adjusted for severity, complexity, and comorbidity), the difference was even larger—after adjustment, the care-coordination group

showed 54.5% shorter average lengths of stay than the usual-care group ($p < 0.002$). Thus, after case-mix adjustment, the average length of stay in the care-coordination group was nearly 5 days shorter than the usual-care group.

Similar differences were found for hospital charges. Hospital charges in the care-coordination group were 22.5% lower than in the usual-care group ($p < 0.017$). When adjusted for case mix, the hospital charges in the care-coordination group increased to 33.2% lower than in the usual-care group. Had the average difference in hospital charges been applied to all members of the care-coordination group, a cost savings of more than \$200,000 (in 1995 dollars) would have been realized.

Perhaps, even more remarkable is that these results were obtained after four outliers from the usual-care group were eliminated from the dataset. Because of extensive variability in the samples, an outlier analysis was carried out and, based on Cook's *D* statistics, four outlier cases were identified. All four of the cases were from the usual-care group and together, had they not been excluded, would have accounted for 428 hospital days, or 16.5% of all the hospital days and 13.5% of all hospital charges in that group. Although it is reasonable to exclude such cases from statistical analyses, it should be noted that these four cases were real individuals and represented the type of problems that care coordinators help resolve. One of these four cases, for example, was a 61-year-old woman in the usual-care group who was hospitalized for many months following admission for adverse side effects of medication and broken facial bones which were likely due to a fall. It is highly likely that this lengthy inpatient stay was not the result of a medical decision. Rather, it was likely due to a problem in discharging the patient such as the family or provider being unwilling to receive her. In the study reported below (Walsh et al., 1997), one case was found of an 85-year-old woman admitted for a cerebrovascular disorder who had remained in the hospital for 228 days. In such cases, the DD Health Home nurse practitioners, carrying out care-coordination activities would, no doubt, have helped to resolve the circumstances that led to such a long hospital stay.

The final study in this series (Walsh et al., 1997) analyzed larger population-based samples, using data collected by a statewide commercial health care data compiler, to examine the impact of care coordination. Hospital admissions from 5 years over the course of a decade (1983, 1985, 1987, 1989, and 1991) were used to compare a care-coordinated group from one hospital ($n = 692$) to a statewide usual-care group ($n = 22,294$) from other hospitals across the state. Although the findings in this study do not directly

replicate the two-group comparison approach of the two studies described above, results showed that, over the study years, per-case hospital costs for the group of patients from the hospital including the DD Health Home patients (the coordinated dataset) increased far less (43.3%) than per-case costs in either the general developmental disabilities population (97.1%) or the nondisabled population in general (124.7%). These findings, once again, point to the beneficial impact of care coordination on hospital costs.

At a time when health care services in many states for persons with I/DD are not integrated, with providers dispersed in various "silos" that further inhibit coordination, the lesson in these utilization studies continues to be relevant—that is, that health care coordination represents an efficient component of primary care. Furthermore, health care models, such as the DD Health Home, that have strong care-coordination components, are likely able to reduce the costs of care for patients with I/DD by providing an integration function across different elements of the health care and wider service systems.

Not only did these studies provide initial validation for the DD Health Home model but they replicated other findings that were being reported in the literature for similar populations such as children with chronic conditions (Liptak, Burns, Davidson, & McAnarney, 1998). Thus, the findings were seen as important and very relevant to questions about the costs of provision of primary care and care coordination to individuals with I/DD (Kastner & Walsh, 1999).

4.3.2. Recent Utilization Analyses

In the late 1990s and early 2000s, the DD Health Home office location moved from the original hospital base to a number of integrated community-based office settings. At the same time, the State of New Jersey began to move the health care for Medicaid-eligible individuals, including those with I/DD, from fee-for-service Medicaid to Medicaid managed care. To assure continued funding for the model, contracts with Medicaid HMOs were developed and the challenges of serving I/DD patients through Medicaid managed care were addressed (Kastner, Walsh, & Criscione, 1997a, 1997b; Ronder, Kastner, Parker, & Walsh, 1999; Walsh & Kastner, 1999).

The movement of patients into Medicaid managed care provided additional opportunities to evaluate costs and utilization in the DD Health Home model. During the past decade, the model has been evaluated in relation to payment systems operating in managed care networks. A common measure of economic performance in managed care is the health

benefits ratio or HBR. The HBR is the fraction of health care dollars (or premium payments) spent by HMOs on actual health care services. The industry standard for HMOs to devote to the HBR is approximately 88%. An economic study prepared by an HMO partner of the DD Health Home in 2004 of its New Jersey I/DD, Medicaid-only product line found an HBR of 75% for group members who received their health care through the DD Health Home—a substantial savings from the standard. In contrast, the overall average HBR for all of its SSI beneficiaries during the same year was 102% showing that there were actually losses associated with that population.

Another way to assess the impact of the savings is for the patient panel as a whole. Taken together, the annual health care cost savings for 1350 patients in the model at the time were, based on the HBR of 75%, approximately \$3 million per year (assuming a premium of \$700 per person per month and comparing the DD Health Home group to the 102% HBR for SSI beneficiaries).

These identified savings are often in the form of reduced emergency room use and fewer hospital admissions. To look at specific types of utilization, New Jersey State Medicaid claims data were recently examined to compare hospital utilization of patients enrolled in the DD Health Home model with patients enrolled in Medicaid managed care but not in the DD Health Home (Walsh, Kastner, & Dixon-Murriell, 2012). Using Medicaid claims data for individuals with I/DD derived from a single HMO, 185 patients receiving care through the DD Health Home who had either one or more hospital admissions or visited an emergency room during 2007 ($n = 85$), 2008 ($n = 52$), or 2009 ($n = 48$) were identified as the DD Health Home group. These patients were matched by age and gender to randomly selected patients who received Medicaid managed care, but were not patients of the DD Health Home (the usual-care group). Three measures of hospital utilization were analyzed: (1) the number of emergency room visits per year; (2) the number of inpatient hospital admissions per year; and (3) the average length of stay, in days, across all inpatient stays by each individual.

Results indicate that during the 3-year study period, patients in the usual-care group averaged 6.59 emergency room visits per year compared to DD Health Home patients who averaged only 2.05, a reduction of 68.8% (see Table 3). Similar differences between the two groups were found for the number of hospital admissions with the usual-care group averaging three times as many admissions (1.29 per person per year) as the DD Health Home group (0.43 admissions per person) (Table 3). These are striking differences

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Table 3 Means and SDs for outcome measures (3 years)

Outcome measure*	DD Health Home group		Usual-care group		p Value
	Mean	SD	Mean	SD	
Emergency room visits	2.05	2.37	6.59	16.11	$p < 0.001$
Emergency room visits (outliers removed)	2.05	2.37	4.24	5.49	$p < 0.001$
Hospital admissions	0.43	0.80	1.29	4.28	$p < 0.007$
Hospital admissions (outlier removed)	0.43	0.80	0.91	2.11	$p < 0.008$
Average length of hospital stay	1.60	3.53	1.58	3.49	Not significant

* All outcome measures are *per person per year*.

attesting to the importance of the health home approach. Group differences in the average length of hospital stays were not significant.

Overall levels of emergency room use in this study are likely to be high in relation to national norms. New Jersey is unique in that long-term care staff members are required by a state law, Danielle's Law (2003), to call 9-1-1 when they believe that a person with I/DD is experiencing a life-threatening event or illness. Because the law includes individual civil penalties, it has emerged as a major driver of emergency room utilization for this population in the state. This fact, along with the large SDs in the usual-care group, once again suggested that there were disproportionate values, or outliers, in the dataset. To identify outliers an arbitrary, but generous, figure of more than 40 emergency room visits per year for an individual patient was adopted as the criterion for a case to be considered as an outlier in the emergency room data. Remarkably, a search of the data identified five individuals who exceeded this criterion—all of whom were found in the usual-care group. Together, these five subjects alone accounted for 457 visits to the emergency room over the 3-year study period! Individually, these five outliers accounted for 119, 62, 42, 118, and 116 emergency room visits, respectively.

As in one of the utilization studies reported earlier, the data were reanalyzed with the outliers removed. Without the five outliers, the group difference for emergency room visits was somewhat attenuated but remained statistically significant (see Table 3). Similarly, a single outlier with 50 hospital admissions in a single year was found in the usual-care group when the hospital admission criterion was set at more than 20 in a given

year. An attenuated group difference was again found but remained statistically significant when the data for hospital admissions was reanalyzed without this outlier (see Table 3).

As intimated previously, searching for outliers in health care datasets for individuals with I/DD often leads to surprising cases of utilization. In fact, the criteria used here to define outliers (i.e. 40 emergency room visits or more than 20 hospital admissions per year) is far removed from what would be found in the general population (on the order of about 0.4 emergency room visits and 0.2 hospitalizations per person per year) (National Center for Health Statistics, 2012). Again, although removal of outliers from the data analysis may help to clarify the nature of the data, all of the outliers identified are actual cases and show how, without care coordination, health care utilization can skyrocket in the I/DD patient population. Although the DD Health Home is able to identify these cases and avoid such utilization, the significant group difference without the outliers suggests that the model also impacts cases that are not so extreme.

With regard to utilization costs, any approach that can reduce overutilization can be seen as positive. From the data described above, managed care alone did not serve as a control on excessive utilization because all of the cases in both groups were enrolled in managed care. In fact, there were striking cases of overutilization in the usual-care patients, despite their enrollment in managed care. Thus, these data show that the DD Health Home, with its critical care-coordination function, reduced both emergency room visits and hospital admissions.

These more recent utilization results are also interpretable within the triple aim of health care, specifically the third part of the triple aim—reducing the costs of health care for populations. Without doubt, health care cost savings are realized through the use of the DD Health Home. Consider the group difference found in average number of emergency room visits, excluding the outliers—2.05 visits for the DD Health Home group versus 4.24 for the usual-care group. Over the 3 years of the study, this mean difference would account for 186 visits in the first year, 114 in the second year, and 105 in the third year—or 405 emergency room visits in all. According to the Medical Expenditure Panel Survey (MEPS, 2009), the average cost of an emergency room visit in America in 2009 was \$1318; therefore, for the 405 emergency room visits alone that the DD Health Home avoided there would be a savings of over \$500,000. The same calculation for hospital admissions reveals that the DD Health Home would have avoided 109 hospital admissions. MEPS estimate of average hospital

charges in 2009 for a single inpatient encounter was \$17,089 resulting in a savings of more than \$1.86 million. In short, with regard to the part of the triple aim having to do with reducing the population costs of health care, the DD Health Home clearly achieves such savings.

5. CONCLUSIONS AND LESSONS LEARNED

Many forces, such as state Medicaid budgets, the Affordable Care Act, new payment methods and systems, and the emergence of various approaches to managing care, are changing how health care is delivered to Americans, including persons with I/DD. These changes are likely to reshape the traditional safety-net providers who served this population and will prompt movement of persons with I/DD into normative health care systems. Although inclusion in larger health care systems may be beneficial for some individuals with I/DD who do not have many health concerns, for those with more health care needs, movement into mainstream health care structures could be problematic.

Still, health care reforms, as well as innovations in the practice and delivery of health care, hold great promise for all patients, including those with I/DD. However, this promise will be empty if problems of health care access continue to plague the population, or if access is achieved but there are no appropriate services, or if limits are placed on those services that are available. The realization of the triple aim of health care—better health care experiences, improved health outcomes, and cost efficiencies—must apply to this group just as it does to patients without disabilities. If these aims are not achieved, persons with I/DD may continue to be underserved despite improvements in the overall health care system.

One way to assure inclusion in the complex and changing American health care landscape for individuals with I/DD is to create medical homes that have the capability to provide specialty care to the I/DD population while also securing a place in the larger health care system. The DD Health Home described herein is such a medical home. To survive in the general health care marketplace, the DD Health Home must achieve the contemporary health care goals in the triple aim and, at the same time, create fundamentally sound payment structures. Prospective reimbursement systems for specialized I/DD medical homes must take into account the barriers to health care in this group, the challenges of providing medical care, and the need for health care coordination.

Health care providers for this population need to come to an understanding of the health care reform and become familiar with new organizational patterns such as HMOs and ACOs. In fact, it is possible in the future that DD medical homes, functioning as ACOs, could contract directly with states to provide care to this group. Over the past 25 years, the evolution of the DD Health Home has addressed these concerns as well as the goals of the triple aim and much has been learned.

First, the model required a knowledge base upon which to build practice patterns for patients with I/DD. Although the DD Health Home has contributed to this knowledge, practice research will always be needed and beneficial. Re-engineering health care practices and creating I/DD medical homes require a steady flow of new knowledge. At the same time, such models can provide an important platform upon which to conduct clinical research on this population.

Second, the DD Health Home has demonstrated that primary care for individuals with I/DD actually benefits by incorporating basic services in selected specialty areas. The common comorbidities presented by the I/DD population, especially in mental health and neurology, are best treated in a coordinated manner. Such an approach results in better outcomes, lower costs, and increased patient satisfaction. The realization that better outcomes became possible when the health care encounter was re-engineered to include specialty care recognized the growing importance of "integration" in health care. Over the years, in this model, it became clear that integration is vitally important to good patient outcomes.

Third, in keeping with new approaches to primary care, the DD Health Home has shown that patients with I/DD can be successfully treated in primary care settings by nurse practitioners. Although nurse practitioners are being increasingly included in primary care practices, they are often in secondary roles; in the DD Health Home, the main primary care practitioner is the nurse practitioner. The use of nurse practitioners in primary care roles has added to the value of internal medicine physicians in the model. It has permitted the expansion of the physician's role to include the monitoring of the health of an entire practice in addition to supporting the clinical practice of the nurse practitioners.

Fourth, the DD Health Home has demonstrated that payment models are important and that prospective payment arrangements are highly beneficial to the operation of the model. However, as the health care reform progresses, other payment alternatives will present themselves. An exciting opportunity in the future may be serving persons with I/DD through ACOs.

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Fifth, evaluation of the DD Health Home has benefited from the analysis of clinical and systems outcome data. These data, in turn, have been linked to changes in the delivery of health care through the model. One example is that the results of clinical studies were used to alter medical practice. Another example was that, as the impact of care coordination became clearly validated, it was an easy step to move to examining other outcomes—such as patient satisfaction and quality of care.

Finally, experience in the DD Health Home clearly revealed the extent of inefficiencies that exist in the health care of this group. Studies of the model uncovered excessive numbers of hospitalizations and emergency room visits—even for patients enrolled in managed care programs. Future work needs to continue identifying and addressing such inefficiencies in the system. For example, future studies might profitably examine pharmacy costs or DME consumption. Beyond that, it is possible that health home practice models may reduce reliance on long-term care. Most professionals in the field have encountered cases in which long-term care placement has been sought primarily because it provided access to clinical services. Unfortunately, all of these inefficiencies simply waste valuable resources and have a negative impact on the overall quality of care.

In the end, the DD Health Home is an important primary care model that can facilitate the development and delivery of high-quality health care to individuals with I/DD. Work to date shows that the model is efficacious and is able to address the triple aim of health care—better care, better health, and lower costs. Although the DD Health Home presents an approach to developing high-quality health care for individuals with I/DD, there is much to do.

Nationwide, many, if not most, patients in this group are still struggling for access in Medicaid fee-for-service systems, or increasingly are being enrolled in managed care structures which may further inhibit choice without providing any offsetting benefits. In this paper, we have described an alternative model of health care—the DD Health Home—that is normative, integrated, and appropriate to the needs of persons with I/DD.

Fortunately, the DD Health Home model will continue to be a subject of study as the model received a 3-year federal demonstration project award from the Center for Medicare and Medicaid Innovation of the Centers for Medicare and Medicaid Services. This will allow for the opening of additional DD Health Home offices in New Jersey, New York, and in Little Rock, Arkansas. As part of the demonstration program, outcomes studies such as those reported herein will continue.

A decade ago in the surgeon general's report, a gap was identified between the health care available for most Americans and the care available for individuals with I/DD. This gap has not yet been closed, although the current impetus toward health care reform in America is promising. Empirically validated clinical models that can be implemented through viable business models are needed. The DD Health Home is one such model.

By replicating and expanding the DD Health Home model, public and private entities can begin to reform health care for persons with I/DD. Implementing such models will begin to close the gap in health care experienced by persons with I/DD. Closing the gap, in turn, will assure that all individuals with I/DD have access to high-quality, appropriate, coordinated health care provided in normative community-based settings. It is care such as this that will achieve the triple aim of health care. Implementing models such as the DD Health Home to close the gap and achieve the triple aim would represent true health care reform for persons with I/DD.

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