A Survey Assessing the Presence of "Medical Home" for Adults with Disabilities in Connecticut

MARY BETH BRUDER, PhD, CRISTINA MOGRO-WILSON, PhD, GERARD J. KERINS, MD

ABSTRACT—*Background:* The medical home model has been recommended as the best design for health-care management for individuals with disabilities by the American Academy of Pediatrics and the American Academy of Family Physicians. As set forth by these guidelines, a medical home contains the following elements: access to health care, usual source of care, personal doctor or nurse, referrals for specialty care, coordinated care, and person-centered care. *Objective/hypothesis:* This study aimed to gather information from adults with disabilities in Connecticut, and the barriers to achieving the medical home model. The study focused on each of the components that make up the medical home model definition. *Methods:* An adult with a disability was defined as a person 18 years or older with any physical or mental disability that significantly impacted one or more major life activities, as defined by the Americans with Disabilities Act. The adults with disabilities were recruited by email through a variety of list servers and flyers that were mailed to employers of people with disabilities. The study consisted of 88 adults with disabilities who were interviewed via telephone with a 54-item survey that was developed based on the research of medical home models. *Results:* The most common types of disabilities represented were physical (51%), psychiatric (28%), and neurological (24%). The results of the study found that 22% of participants were found to have access to health care, 92% of participants reported they had a usual place they go to receive health care, 77% of participants reported having no problems with the process of referrals, 37% of participants were found to have adequate coordinated care, and 90% of participants were identified as having person-centered care. *Conclusions:* Overall, only 7% of participants met the criteria for all aspects of the medical home model. The conclusions drawn from this study indicate a need for increased access to health care, more efficiently designed coordinated care, and more accessible referrals to specialists for adults with disabilities, with access being the largest barrier to adequate health care.

Introduction

THE medical home, also known as patient-centered medical home, is defined as an approach to providing comprehensive primary care that facilitates partnerships between individual patients and their personal physicians, and, when appropriate, the patient's family.[1] The medical home is a concept that was initially applied to the population of children with special health-care needs in 1967.[2] The American Academy of Pediatrics (AAP) first introduced the concept as a vehicle to ensure that children, especially those with chronic conditions, had access to a health-care system. The medical home is not a physical location but a model of care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[3-5]

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SPECIAL

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Though the medical home concept was originally targeted toward children with special needs and chronic conditions, the medical home concept has recently been expanded into adolescence and adulthood.[6]

There is a clear need for a medical home for adults with disabilities, particularly because many more children with disabilities are living into adulthood with the assistance of medical supports and technology.[7] For example, the population of those with Down syndrome continues to increase as medical supports enable many to live well into adulthood.[8] Many of these individuals will have medical conditions that need ongoing management in order for them to achieve a high quality of life.[9] As found in a study by Havercamp et al,[10] individuals with disabilities are significantly more likely than those without disability to suffer from chronic health conditions.[11] These include obesity,[12-14] high blood pressure, arthritis and diabetes.[11] These findings are problematic in light of data suggesting existing disparities in access to health care and medical care utilization for adults with disabilities.[6] A survey of 206 physicians providing services to adults with disabilities identified a number of factors that negatively affected care to these patients .[15] Chief among these were communication issues followed by continuity of care, time, and insurance coverage. When queried on how to improve care to patients with disabilities, physicians ranked the provision of continuous care as the first factor for improvement, followed by availability of training for physicians. Ninety-one percent of the respondents had no formal training regarding the care of adults with disabilities, and 71% indicated they would benefit from continuing education on this topic.

In 2004 The American Academy of Family Physicians (AAFP) launched the Future of Family Medicine report and project, calling for a "personal medical home" for all Americans, children and adults alike. In 2006, the AAFP endorsed a policy which states that "patients need a personal medical home that serves as the focal point through which all individuals—regardless of age, sex, race or socioeconomic status—receive a basket of acute, chronic and preventative medical care services."[16(p7)] This was followed in 2007 by a joint statement by the American Academy of Family Physicians, the American College of Physicians, the American Osteopathic Association, and the AAP on the patient-centered medical home. This document specified that patient-centered medical homes should offer personal physicians for patients, a physician-directed medical practice, whole-person orientation, coordinated care, quality and safety, enhanced access, and an appropriate payment structure.

The purpose of the current study was to assess the presence of a medical home among adults with disabilities in Connecticut. We developed a questionnaire using criteria for a medical home derived from Strickland, McPherson, Weissman, van Dyck, Huang, and Newacheck[17] who described the characteristics of a medical home as defined by the American Academy of Pediatrics.[3] Additional criteria were added based on other pediatric medical home models[18] and a proposed advanced medical home model for adults.[19] In total, the authors used the following components as the criteria for a medical home: 1) Access to health care; 2) Usual source of care; 3) Personal doctor or nurse; 4) Referrals for specialty care; 5) Coordinated care; and 6) Person-centered care.

Methods

Study Participants.—The target population consisted of adults with disabilities who live in Connecticut. For purposes of this survey, an adult was considered to be anyone at least 18 years old and a disability was defined as any physical or mental disability that significantly impacts one or more of the major life activities as defined by the American's with Disabilities Act. To recruit participants, e-mails describing the survey were sent to individuals on the UCEDD list-serve (n=900), as well as individuals throughout the disability community. Flyers were distributed about the study and posted by agencies statewide. Individuals interested in the survey were asked to call to schedule a time to complete the survey. No direct phone calls were made to solicit participation.

Instruments.—The 54-item telephone survey was developed by selecting criteria of a medical home from a variety of sources.[3,17,18] The survey contained demographic questions about the respondents and their disabilities. Survey questions were asked about the primary-care physician, access to care, coordination of care, office and staff of primary-care physician, accessibility, transportation, delay of services, and health insurance. The telephone survey was conducted by a trained interviewer. The survey lasted approximately 20 minutes. All procedures conducted were approved by the Institutional Review Board. Reliability was calculated for coding interview responses and for data entry. To check reliability for coding interview responses the principal investigator listened in on 17% of the interviews and filled out the survey form independently of the interviewer. Reliability was obtained at 98% for coding interview responses. To assess reliability of data entry, 19% of the surveys were randomly pulled by a research assistant and reentered. These data were then compared with the originally entered data. Reliability was obtained at 99% for data entry.

Results

Demographics.—A total of 88 surveys were collected. The vast majority of participants are white/Caucasian (91%) and roughly two-thirds are female (66%). Participants tended to be middle aged, with roughly three-quarters falling into the 41-year to 60-year age range. Participants reported having a variety of disabilities and were able to indicate more than one disability. The most common among disabilities was physical disability (51%) (Table 1).

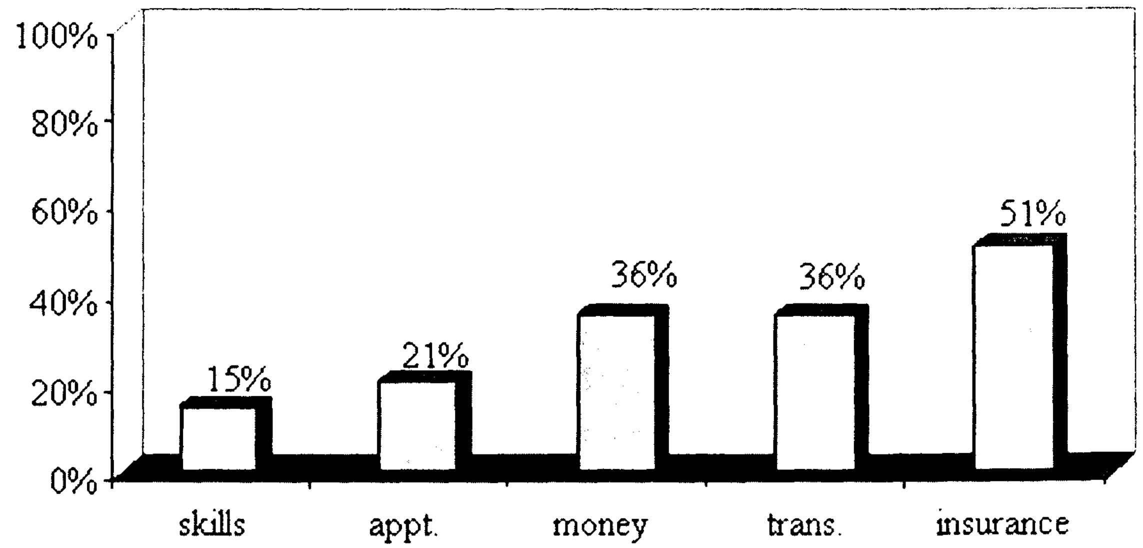
Table 1.—Demographics

Race/Ethnicity (n = 88)	
White/Caucasian	91%
African American	6%
Hispanic/Latino	2%
Asian	1%
Type of Disability (n = 88)	
Physical disability	51%
Mental Health	27%
Neurological	24%
Sensory Impairment	14%
Cognitive/learning	9%

Components of a Medical Home

Access to Health Care.—The first component used to describe a medical home was access to health care which included access to a provider at a location, access at the appropriate time, physical access, and financial access. In total, 22% of participants were considered to have health care that satisfied all four requirements of access. While all of the participants reported having a place where they usually go to receive health care, 60% reported delays in receiving health care in the past year. The participants who reported delays were asked the cause of the delay (Fig. 1). Having insurance that did not cover the type of health care needed (insurance) was the number one reason given for delays, followed by transportation issues (trans.), and not being able to pay for care (money). Additional reasons included inability to schedule an appointment soon enough (appt.), and unavailability of a provider with the required skills (skills). Eleven percent of participants reported that the type of care needed was not available in their area, 11% reported they could not get approval from their primary-care doctors, and 11% reported that going to appointments conflicted with other responsibilities. Other reasons for delay included: difficulty reaching the health-care provider on the telephone (9%); language, communication, or cultural problems (8%); waiting too long to receive care (4%); an accessibility issue, at home or at the office (2%); and the office not being open when the person could go (2%).

To provide more information about access to health care, participants were asked questions addressing transportation and physical accessibility. The vast majority reported traveling to appointments either by driving themselves (40%) or having someone else drive them (32%). Additional sources of transportation included ambulance (7%) and walking (5%). Accessibility to the office and examination room was reported as something that was a concern for roughly half (49%) of all participants (Fig. 2). For these participants, the major barrier was a lack of motorized, adjustable-height examination tables. Fifty-two percent of participants reported that their physicians did not have adjustable-height tables and 15% reported they do not know. Having accessible entrances at the site of service was also an issue for 19% of participants.



*** Participants were allowed to provide more than one reason for delays.**

Figure 1.—Reason for delays in health care (n = 53).

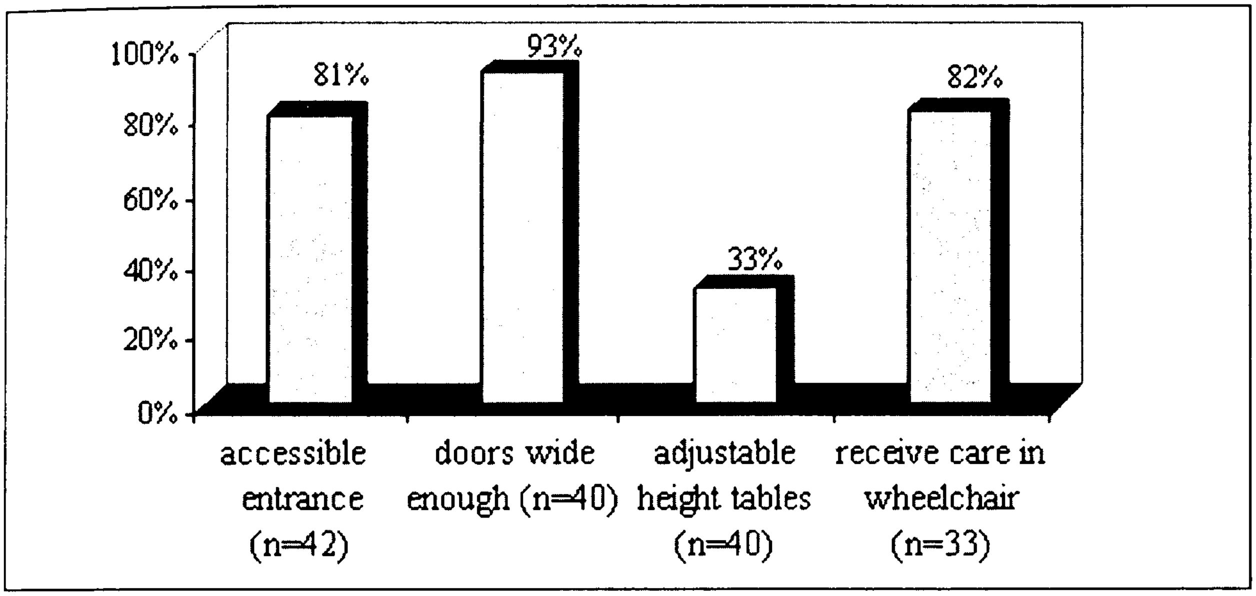


Figure 2.—Percent reporting characteristics of office rooms as accessible.

To measure financial access to health care, questions were asked about the presence of health insurance, as well as the adequacy of the health insurance for all needed services. For the 88 participants that responded to the question of health insurance, most had health insurance (99%). The most frequent types of insurance for participants were Medicaid and Medicare (31%), followed by Medicare alone (25%) and private insurance alone (21%). In addition, 6% of participants reported having private insurance and Medicaid, 5% reported having private insurance and Medicare, and 2 % reported having private insurance, Medicaid, and Medicare. Of the participants who had health insurance, 57% reported their health insurance did not pay for all of the needed health services and 3% reported that they did not know.

Usual Source of Care.—The participant had to indicate that there was a usual place he or she received care. Ninety-two percent responded in the affirmative. The doctor's office (69%) was the most common place participants went to receive routine care (Fig. 3).

Personal Doctor or Nurse.—The third component of a medical home was having a primary care doctor or nurse. The overwhelming majority of participants (96%) responded that they were thus served.

Additional information collected from survey participants focused on the characteristics of the primary doctor or nurse. The most common types of providers were: primary-care physicians (44%); other specialists, such as surgeons, cardiologists, gynecologists (27%); and internists (18%). Other providers included: visiting

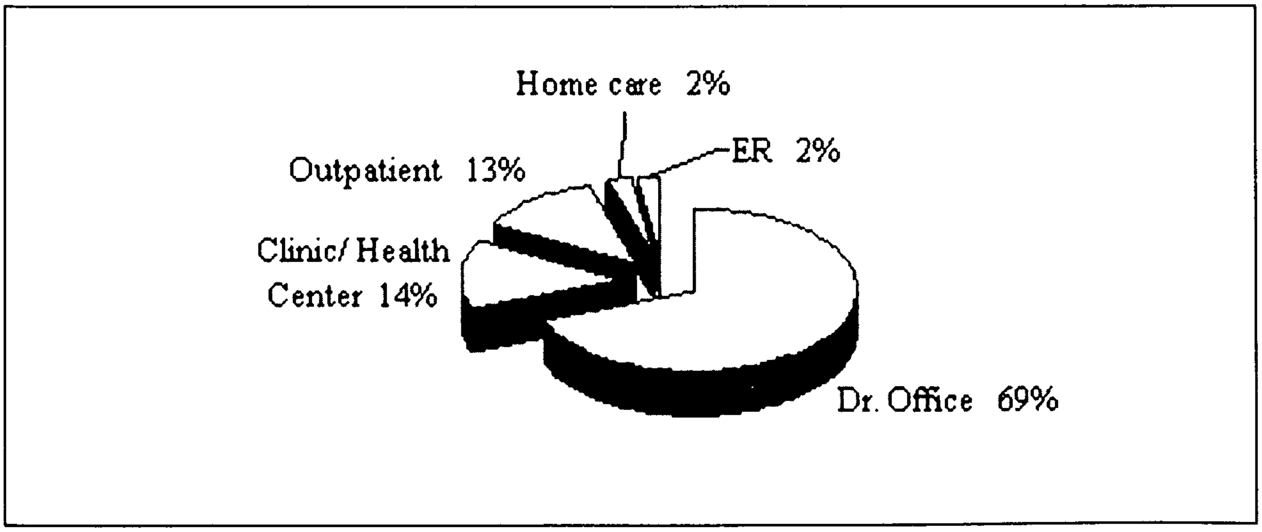


Figure 3.—Usual place for routine preventative care (n = 88).

nurse/ home-health aide (4%); nurse practitioner (2%); naturopath (2%); physician's assistant (1%); and physical therapist (1%). The care was primarily provided at a doctor's office (69%), a clinic or health center (14%), or a hospital as an outpatient (12%), with a few respondents noting they received health care primarily from a hospital emergency room (2%) or at home (2%).

Several participants (43%) reported having the same primary-care provider for over 10 years. Roughly a quarter of participants (23%) had the same primary-care provider for four to nine years and one-third of participants had the same primary-care provider for three years or less (Fig. 4). More than half of the participants (58%) reported that they were always allowed enough time during appointments. Eight percent of participants reported that they never had enough time during appointments.

Referrals for Specialty Care.—Survey respondents were asked about their use of specialty care. In particular, they were asked if they had problems getting referrals to specialty care. Of the 68 participants who reported that they needed referrals in the past year, approximately three-quarters (77%) reported no problems with the process.

Coordinated Care.—The measure used to assess coordinated care was a composite of questions about care coordination in a timely manner, and excellent or good perceived communication between medical providers. For care coordination to be considered adequate, the participant first had to indicate that he or she received care coordination when needed and then that he or she believed the communication between doctors was either excellent or good.

Overall, 68% (n=60) of participants reported needing help with coordination. Of these individuals, 52% (31) reported they had received the help they needed to coordinate care. Of the 52% who received help, the majority, 71% (22 of 31), reported that communication between their doctors was either excellent or good. Coordinated care, therefore, was found to be adequate for 37% of these participants who reported needing help with coordination.

Person-Centered.—Person-centered care, as defined for this study, occurs when providers listen and communicate with clients to consider patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. To assess the presence of person-centered care, participants were asked if their physicians listened to concerns and questions, and if they used helpful ways of communicating (e.g. explaining terms in a manner that is easy to understand). To be considered to have person-centered care, participants had to answer yes to both questions. Ninety-five percent of participants reported that physicians listened to their concerns and questions, and 90% reported that helpful ways of communicating were used. In total, 90% of participants were identified as having person-centered care.

Medical Home.—To summarize the data to assess the presence of a medical home, responses were combined across all criteria. There was great variety with regards to the percentage of participants who were able to meet the respective criterion(a). Primary doctor or nurse criterion was met by 96% of the participants. Usual source-of-care criterion was met by 92% of the participants. Person-centered care criteria were met by 90% of the participants.

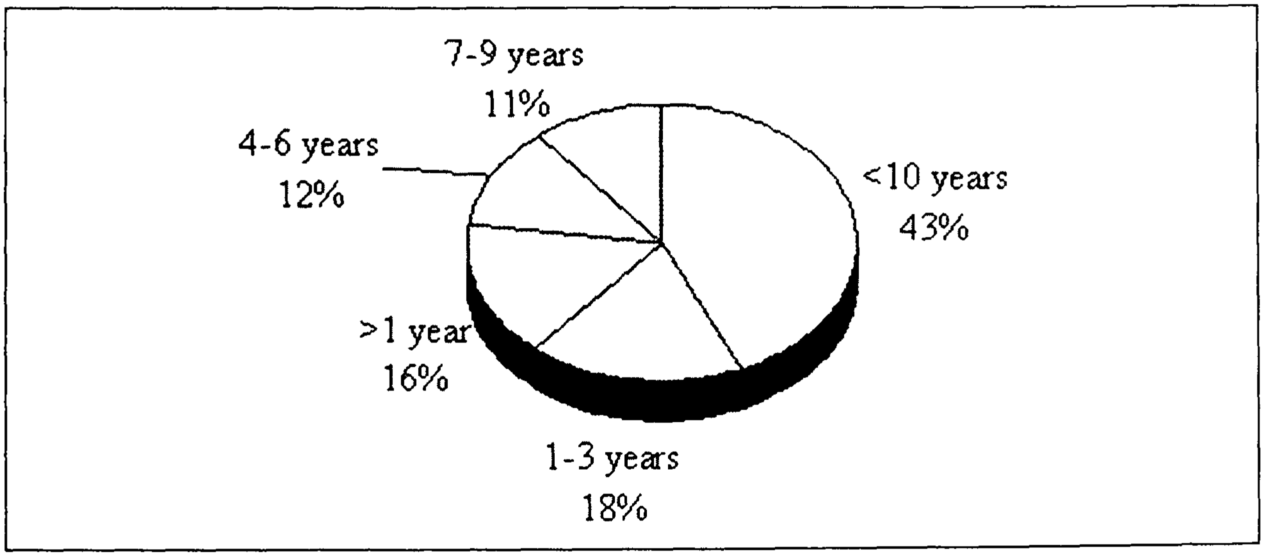


Figure 4.—Length of time with primary-care provider (n=84).

Referrals for specialty care criteria were met by 77% of the participants who required referrals. Coordinated care criteria were met by 37% of the participants who needed assistance. Finally, all four components of access-to-health-care criteria were met by 22% of the participants (Fig. 5).

In total only 7% (n=6) of the participants were able to meet all six components of a medical home. The major barrier to a medical home for adults is access to health care. When this component is removed, 38% of the participants meet the remaining components of a medical home. The second major barrier is coordinated care. When this component is removed in addition to access to health care 49% of the participants meet the remaining components of a medical home. The final significant barrier to a medical home for adults is referrals for specialty care. When this component is removed in addition to access to health care and coordinated cared 84% (n=74) of the participants meet the remaining components of a medical home.

Discussion

The concept of a medical home for adults with disabilities is a goal yet to be met for most of the respondents to this survey. Though the concept of a medical home has been advocated for a longer period of time for children than adults,[3,17,18] many of them do not as yet have access to this model of medical care. According to the 2006 national survey of approximately 41,000 children with special health-care needs (CSHCN), only half were reported to have a medical home.[20] This survey also used a multicomponent definition to describe the medical home. Further, this survey documented that variables such as race, ethnicity, income, health insurance and severity of a child's condition limited access to a medical home.

In our study of adults with disabilities, one limitation of the sample was its homogeneity in regard to race, ethnicity and income. Severity of disability was not measured, though all respondents were able to be interviewed which in itself suggests a level of competence within the sample. An additional limitation of the sample was that it was a self-selected group; a subject was required to call/email in order to participate. The homogeneity, competence and self identification of the sample did not assist in the identification of a medical home, only 7% of this sample of adults responded to having all components of a medical home in place. The major barriers identified were access to health care followed by coordinated care, and timeliness of medical care.

As stated, access to health care was the largest identified barrier to the medical home model in this study. Access was evaluated through a number of questions on location, physical access, and financial access. Physical access included appropriate entrances to a medical facility and adjustable equipment (e.g., leg examination tables). Most respondents had access to health insurance, with over half using public programs such as Medicaid and/or Medicare. However, 60% of the sample reported delays in receiving needed health care, and lack of insurance coverage was identified as a major reason for this. These findings replicate findings from a larger survey of over 1,500 older adults with disabilities that found a large proportion reporting cost-related barriers to care.[21] It seems that while many adults with disabilities have public or private sources of insurance, they are not adequate to cover all the health-care needs of the population.

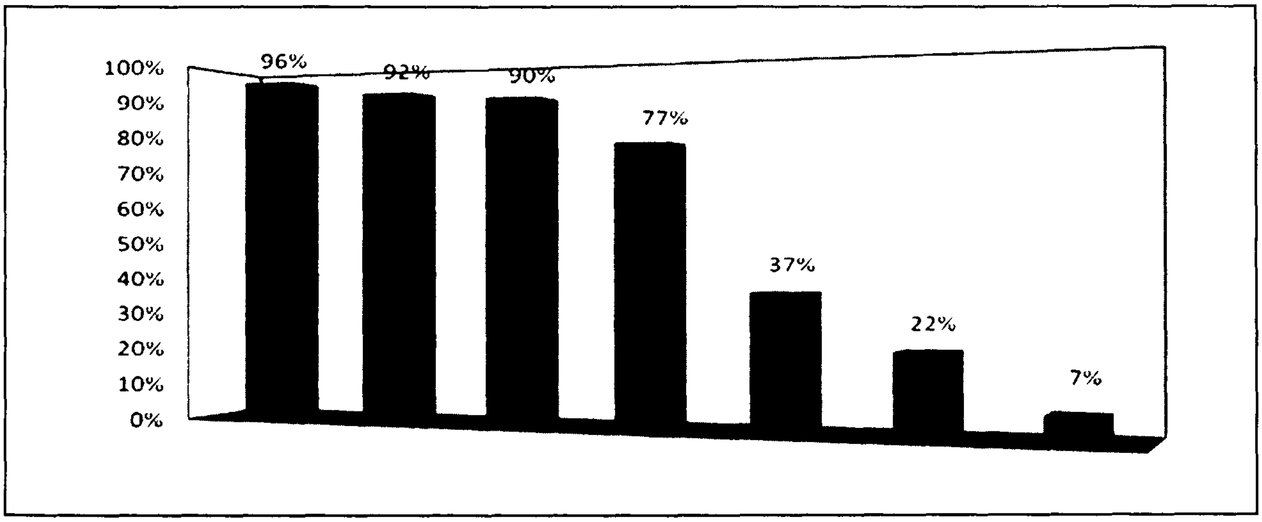


Figure 5.—Percent of respondents fulfilling each component of a medical home.

The issue of coordinated care is also of prime importance. Persons with disabilities usually require the support of others to achieve and maintain a high quality of life. This usually includes support by service providers from multiple areas, including the health-care disciplines. In the history of the medical home, care coordination is more likely to be in place for children with special health-care needs.[22,23] Both disabled populations (children and adults) have experienced difficulty coordinating the many providers and services needed on a daily basis. Though only one component of a medical home, coordinated care is one of the most important, and as such, demands attention as the move to the medical home model becomes operational.

Health-care reform remains a national priority. As we establish a health-care network that is responsive to every American's needs, we must not forget the accommodations necessary for those with disabilities. Among these needs are physical accessibility, access to medical care in a timely manner, and help coordinating care across numerous specialists. Only when these requirements are met can we begin to measure the impact of a medical home on a person's health status and quality of life. As we consider how to reform, streamline and expand the health-care infrastructure, it is incumbent upon us to ensure that reform does not leave disabled adults without appropriate and accessible health care.

Conclusion

In conclusion, the findings of our survey revealed the lack of medical home models being utilized by adults with disabilities and their physicians in Connecticut. The model is recommended as best practice by the American Academy of Pediatrics and the American Academy of Family Physicians for all individuals with disabilities, and was only being fully utilized in only 7% of the of the adults with disabilities in our sample. The population of adults with disabilities have unique needs as was highlighted in this study, and the benefits of a medical home model have been recommended as the foundation for improved health-care access, coordination, and overall service for those individuals with disabilities. Future research should include larger, more diverse samples and longitudinal work to establish the relationships between health-care status and quality of life for persons with disabilities.

Acknowledgements

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