

Left Out in the Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts



December 2008

Prepared by



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Left Out in the Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts

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ACKNOWLEDGEMENTS

In the past decade, we have seen a flurry of activity in health care and health care reform in Massachusetts, not least of which was the establishment of the ground-breaking health care legislation that seeks to have all Massachusetts citizens insured.

Prior to health care reform, Massachusetts' then Governor Mitt Romney significantly reduced the MassHealth (Medicaid) entitlement for adult dental services. In an earlier administration, CommonHealth¹ was made less accessible by increasing insurance premiums and co-pays.

The Arc of Massachusetts and other disability organizations felt powerless as we saw the ebbs and flows of these changes. Our resources in governmental affairs were not adequate to address health care as a separate activity, despite the anecdotal reports and publications, such as the Surgeon General's report (2002) on the barriers to quality health care for individuals with intellectual and/or developmental disabilities (ID/DD). In our state, even when efforts were made to assess the services available to individuals with disabilities, the issues facing those with ID/DD were not necessarily included in reports (demonstrated in Brawarsky, Brooks, Mitra, & Chung, 2001).

This report is the first step in a systematic effort to address the health care barriers facing individuals with ID/DD. We would like to acknowledge those who have made this report a reality. In 2006, The Arc of Massachusetts' Board of Directors established a Health Care Steering Committee, so that we could begin our efforts. The members of the Committee include Chris Andry, Ph.D. (Director of Pathology, Boston Medical Center); André Blanchet, M.D. (Medical consultant to the Medical Safeguarding Initiative Massachusetts and President of the Board, Shriver Nursing Services); Allen Crocker, M.D. (Children's Hospital); Marc Emmerich, M.D. (Boston's Community Medical Group); Ruth I. Freedman, M.S.W., Ph.D. (Boston University School of Social Work); Robert Harris (Executive Director, CLASS Inc.); Mary Ellen Mayo, RN, MS (Past President of The Arc of Massachusetts); Janet Sweeney Rico, PhD, MBA, NP-BC (Simmons Graduate School for Health Sciences); and Donald Stewart, MBA (The Concurrency Group). This body, assisted by Mary Lou Maloney (Past Legislative Director of The Arc of Massachusetts), defined the objectives of our Project and worked on a foundation proposal. In June 2007, The Boston Foundation (tbf.org) provided the primary support to begin our research. These two developments set the foundation for our work.

The Health Care Project's Research Team members have worked diligently on this study and publication of the report. Our senior research consultant is Ruth I. Freedman, M.S.W., PhD., Associate Professor and Associate Dean for Academic Affairs at Boston University School of Social Work. Dr. Freedman is highly experienced in the field of developmental disabilities, has written numerous publications, and has presented at many national conferences on disability issues. She received the high honor of Fellow Award from the American Association on Mental Retardation in 1999. The Project Director is Amanda D. Nichols, M.S.W. Ms. Nichols has health care advocacy and research experience. She outreached to minority rural residents in Southwest Virginia to inform parents/guardians of the State Children's Health Insurance Program (SCHIP), and her role included research on the health care barriers faced by children enrolled in SCHIP. The Research Assistant is Rolanda Ward, MSW, M.Div., a sixth year doctoral candidate at Boston University School of Social Work. She has had previous

¹ CommonHealth is a special insurance program administered by MassHealth for individuals with disabilities who are employed.

experience managing and directing a project, and also has extensive research skills and experience developing surveys and conducting interviews.²

It is important to recognize other key participants who assisted us to ensure the success of the Project. The following groups and organizations hosted the focus groups: Bay Cove Human Services, Charles River Arc, Department of Mental Retardation³ Brockton area office, Haitian-American Public Health Initiatives, Latin American Health Institute, Minute Man Arc for Human Services, Springfield Multicultural Community Services, and The Arc of Eastern Middlesex. A special thanks to the organizations and groups, including ones previously listed, that collaborated with us during outreach.⁴

We scheduled time with the following Massachusetts' public officials to develop lines of communication:

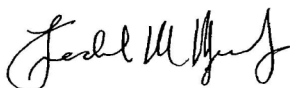
1. Executive Office of Health and Human Services Assistant Secretary for the Office of Disability Policy and Programs, Jean F. McGuire, PhD;
2. Executive Office of Elder Affairs Undersecretary, Sandra K. Albright;
3. Department of Public Health Commissioner, John Auerbach, Medical Director, Lauren A. Smith, MD, MPH, and Healthy Aging and Disability Unit Director, Anita Albright;
4. Massachusetts Rehabilitation Commission Commissioner, Charles Carr; and
5. Department of Mental Retardation Assistant Commissioner for the Office of Quality Management, Gail Grossman.

Although we feel this publication is an important step in identifying the health care issues facing our constituents, we realize progress will be achieved only through the implementation of our recommendations.

We are committed to a vigorous advocacy agenda, which includes the attainment of further resources for the Project in order to effect systems change. We look forward to collaborating with funders, other organizations and agencies in our field, knowledgeable health care professionals, and health care advocates in the broader arena in order to achieve our aims.

Our warm appreciation goes to all of those who assisted in this effort.

Sincerely,



Frederick M. Misilo, Jr., Esq.
President



Leo V. Sarkissian, M.S.W.
Executive Director

² Note from Project Director: Additional contributors to the Health Care Project and this report include The Arc of Massachusetts' Executive Director, Leo V. Sarkissian, M.S.W., as the primary author of the *Project Team Recommendations and Discussion* section of this report and reviewer of final report and The Arc of Massachusetts' Community Relations Manager, Judy Zacek, PhD, as editor and researcher on grants to sustain the Project.

³ The Massachusetts Department of Mental Retardation will be officially renamed the Department of Developmental Services in June 2009.

⁴ Groups include Advocates for Autism; Advocates, Inc; Department of Mental Retardation Area and Regional Offices; Greater Waltham Arc; Massachusetts Advocates Standing Strong; Massachusetts Down Syndrome Congress; Massachusetts Families Organizing for Change; North Shore Arc; The Arc of Greater Boston; The Arc of Greater Lawrence; The Arc of Massachusetts' Government Affairs Committee; The Arc of Massachusetts' Health Care Steering Committee; The Partnership for Healthcare Excellence; Vinfen; and Work, Community, Independence.

THE ARC OF MASSACHUSETTS

The Arc of Massachusetts is a non-profit disability organization. Its mission is to enhance the lives of individuals with intellectual and developmental disabilities (ID/DD) and their families. We accomplish this through advocacy of supports and services based in the community.

The Arc has a strong track record of policy achievements over the past 50 years. These achievements include the establishment of special education, advocating for a community system of supports through the legislature, and the establishment of the “Community Plan” in the Consent Decrees. In the past decade, The Arc of Massachusetts has successfully advocated for expanded funding for graduating students with special needs (Turning 22) and Family Support, among other programs, and participated in three successful legal actions. The Boulet and Rolland Settlements resulted in services to nearly 4,000 individuals. The Arc of Massachusetts’ achievements have helped to advance national policy along with its participation in national policy activities through The Arc of the United States.

In September 2006, The Arc of Massachusetts’ Health Care Steering Committee met for the first time. Its establishment reflected the organization’s grave concern about access to quality health care services in light of the growing complexity of the health care system. It also reflected the governing board’s commitment to establish more organizational capacity to advocate in this area. The committee targeted two goal areas: (a) improve access to high-quality health care and (b) promote healthier lifestyles. The Health Care Project’s mission is to champion access to optimal health care for individuals with ID/DD. Underlying the mission is the belief that all individuals have a right to easily accessible, culturally competent, and high-quality health care in the community.

In June 2007, The Boston Foundation (tbf.org) demonstrated its support through a grant of \$60,000. Year Two funding from The Boston Foundation was received in June 2008. This Project and related health care advocacy activities have received additional funding from organizations throughout the state and the Community Foundation of Western Massachusetts.

PRIMARY FUNDER OF THE PROJECT

The Boston Foundation is one of the oldest and largest community foundations in the nation, with assets of over \$900 Million. In 2007, the Foundation and its donors made more than \$92 Million in grants to nonprofit organizations and received gifts of more than \$155 Million. The Foundation is made up of nearly 900 separate charitable funds, established by donors either for the general benefit of the community or for special purposes. The Foundation also serves as a major civic leader, provider of information, convener, and sponsor of special initiatives designed to address the community's and the region's most pressing challenges. For more information about The Boston Foundation, visit www.tbf.org or call 617-338-1700.

Thanks to the generous funding received from The Boston Foundation for year one, The Arc of Massachusetts has taken a critical step toward assessing the quality of health care services provided to adults with intellectual and/or developmental disabilities in Massachusetts.

The Arc of Massachusetts recently received renewal funding for year two of the Project, which will focus on disseminating the report through community meetings and fine-tuning the policy recommendations discussed in this report.

The following are the specific The Boston Foundation charity funds that donated to the Project in year one and year two: Edith M. Ashley Fund, Irene W. Bancroft Fund, J.E. Adrien Blais Fund II, and Kate Ellis Fund.

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EXECUTIVE SUMMARY

Jane (alias name) became teary-eyed and her voice started to tremble, “*I can’t seem to find that link [for my son].... It’s very difficult ... [and] challenging ... to find the right people to treat him as an adult. ... I’m out in the cold.*” She mustered up strength to continue, “*It’s very, very dim. I feel like I’m very much ... on my own.*”

Jane, a parent/guardian focus group participant, had called numerous nursing services, contacted several organizations and agencies, worked with a number of behavioral consultants, and met with her adult son’s pediatrician to search for answers and to seek help in finding an adult primary care physician (PCP) who was willing and qualified to work with her son, who has autism and self-injurious behaviors. Jane seemed to want her son to reside in the community, but reportedly felt “out in the cold” because other professionals long ago “ran out of ideas” to help meet the health care needs of her son.

The absence of necessary health care professionals and medical services and methods to obtain them leave many families, including Jane’s, with feelings of isolation. Her story and others, unfortunately, are reflected in other articles and research.

BACKGROUND

Health care disparities faced by individuals with intellectual and developmental disabilities (ID/DD) have been reported in journals, reviewed by government entities, and raised by advocacy organizations (Krahn, Hammond, & Turner, 2006). Increased life expectancy of individuals with disabilities and improved medical and assistive technologies have enabled many individuals with ID/DD, even those with complex medical conditions, to reach adulthood and old age (Braddock, Emerson, Felce, & Stancliffe, 2001; Horwitz, Kerker, Owens, & Zigler, 2000). Most of these individuals live in a variety of community settings, i.e., with family members, independently, and/or in community-based service settings, such as group homes and apartments. Consequently, they utilize many community-based services and supports, including primary medical care settings and hospitals.

The medical needs of this population are often overlooked as health systems become more complex and insulated (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, & Maisels, 2006). The Report of the U.S. Surgeon General’s Conference on Health Disparities and Mental Retardation, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (Office of the Surgeon General, 2002) highlighted significant inadequacies in meeting this population’s health care needs and found that individuals with ID/DD experience poorer health and have less access to medical care than the general population.

A major concern is the shortage of qualified, trained health care professionals with in-depth knowledge of the specialized health and mental health needs of this population (Special Olympics, Inc., 2005). Horowitz et al. (2000) highlighted the need for more comprehensive mental health services, ophthalmologic, and dental services for those with DD. Lewis, Lewis, Leake, King, & Lindemann (2002) found serious inadequacies in dental care, pap screenings, and immunization updates.

The *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* (Office of the Surgeon General, 2005) notes the challenges that individuals with disabilities face in obtaining quality health care: communication, social barriers, mobility, and accessibility. Individuals with ID/DD often face cognitive challenges in understanding or recognizing their own health problems, communicating their needs to appropriate health care professionals, and understanding and adhering to health and behavioral treatments. Moreover, cultural and language barriers may further complicate their (and their families') communications and interactions with health care professionals (Henry J. Kaiser Family Foundation, 2007).

The year one goal of The Arc of Massachusetts' Health Care Project was to conduct a needs assessment to assess the quality of medical services received by adults with ID/DD. This report summarizes the year one findings and recommendations of the Project (2007-2008), funded by The Boston Foundation along with additional support from The Community Foundation of Western Massachusetts. The Project's mission is to champion access to optimal health care for individuals with ID/DD. Underlying the mission is the belief that all individuals have a right to easily accessible, culturally competent, and high-quality health care in the community.

METHODS

This study utilized focus groups, informant interviews, and on-line surveys in 2007 and 2008 to obtain health care experiences of adults with intellectual and/or developmental disabilities (ID/DD) and their parents/guardians, community support and health care professionals⁵, state legislators, and health insurance providers. The Project team outreached to a broad and diverse group of respondents in Boston, the greater metropolitan area, and western Massachusetts. See Table 1.

Focus group and informant interview guides and on-line surveys consisted of open-ended questions developed by Project staff members based upon review of prior related research and upon suggestions from The Arc of Massachusetts' Health Care Steering Committee (including family members and health care professionals). Questions elicited participants' first-hand knowledge, personal experiences, and recommendations. The specific questions varied somewhat for the three types of focus groups (self-advocates, parents/guardians, and community support professionals) and three types of key informants (health care professionals, state legislators, and insurance providers). The on-line surveys questions were similar to the focus group questions. Focus group sessions and informant interviews were audio-taped (upon permission) and transcribed, and qualitative analysis and coding of transcript data was undertaken by the three Project researchers, which involved independent and joint review of the transcript data. The on-line surveys were incorporated in the overall analysis when additional issues or themes were identified.

The Health Care Project's study was approved by the Massachusetts' Department of Mental Retardation's Research Review Committee. Self-advocate and parent/guardian participants signed informed consents to take part in the focus group sessions, and all self-advocates were their own guardian. Self-advocate and parent/guardian participants received a stipend for participation, plus reimbursement for transportation expenses.

⁵ Throughout this report, the definition of health care professional includes allergists, dentists, family nurse practitioners, gynecologists, health care administrators/advocates, internists, neurologists, orthopedists, pediatricians, physicians, psychiatrists, registered nurses, and, among others, therapists, such as occupational and speech.

Table 1: Data Collection

Participant	Focus Groups (N)	Informant Interviews (N)	On-line Surveys (N)
Self-Advocate (Adult with ID/DD)*	2		8
Parent/Guardian*	3		35
Community Support Professional (CSP)*	4		41
Parent/Guardian and CSP	1		
Health Care Professional		26	
State Legislator		5	
Insurance Provider		6	

*Note. The number of self-advocates, parents/guardians, and community support professionals who participated in the focus groups were 18, 41, and 57, respectively.

PROJECT FINDINGS

Across focus groups and health care professional informant interviews, respondents identified seven key, salient themes: (a) knowledge, (b) communication, (c) quality, (d) access, (e) insurance, (f) care coordination, and (g) recommendations⁶. The state legislator and insurance provider findings were not included within the salient themes because their experiences and knowledge of the health care needs and barriers for the ID/DD (intellectual and/or developmental disability) population were limited.

Knowledge

Health care professionals lack sufficient knowledge about how to care for patients with ID/DD. Furthermore, they lack knowledge about the specific health care needs of patients who do not reflect the “typical” patient. Across self-advocate, parent/guardian, and community support professional focus groups and health care professional interviews, respondents identified three key categories:

1. Health care professionals lack sufficient training in and exposure to patients with ID/DD
2. Parents/guardians serve as educators of health care professionals
3. Residential staff members lack training and experience regarding the health needs of patients with ID/DD

Communication

The communication skills of health care professionals, self-advocates, parents/guardians, and community support professionals play a significant role in how self-advocates access medical

⁶ The key themes are further discussed, including participants’ quotes, in the *Project Findings* section of the full report.

care. Across all focus groups and health care professional interviews, respondents identified four main categories:

1. Lack of direct communication between health care professionals and patients with ID/DD
2. Lack of communication due to language barriers
3. Lack of information sharing across providers and systems
4. Positive communication experiences, including health care professionals who develop a good rapport with patients and utilize strategic actions to facilitate communication

Quality

Appropriate and positive attitudes, interactions, and processes performed by health care professionals and residential staff members were essential to receiving high-quality medical care. Across self-advocate, parent/guardian, and community support professional focus groups, six key categories were shared by the respondents:

1. Health care professionals' and staff members' bias about and insensitivity to patients' needs
2. Lengthy waits and rushed medical practice atmosphere
3. Negative impact of quality of care based on patients' behavior
4. Inadequate medical care received by patients
5. Lack of resources across agencies, community programs, and medical offices
6. Positive practice atmosphere, including direct communication with patients and accommodating patients' needs

Access

The ability to access timely preventative and as-needed medical care services was vital and very important to all groups. Across self-advocate, parent/guardian, and community support professional focus groups and health care professional interviews, four main categories were identified by the respondents:

1. Problems finding health care professionals, including primary care physicians and medical and non-medical specialists
2. Adults with ID/DD who continue to remain with their pediatricians
3. Lengthy waits and delays experienced after obtaining health care professionals
4. Positive experiences in obtaining health care professionals were identified by one group (parents/guardians)

Insurance

Insurance coverage alone does not ensure access to qualified health care professionals and necessary medical services. Insurance barriers were identified across all focus groups and health care professional interviews. The respondents shared three key categories:

1. Shortage of health care professionals accepting public insurance
2. Lack of adequate insurance coverage
3. Lack of consumer knowledge of insurance system

Care Coordination

Care coordination is not a standard practice for patients with ID/DD. Across self-advocate, parent/guardian, and community support professional focus groups and health care professional interviews, three main categories were identified by the respondents:

1. Informal care coordination
2. The need for formal care coordination
3. Strategies for care coordination

Focus Group & Health Care Professional Interview Respondents' Recommendations

Self-advocates, parent/guardians and community support and health care professionals offered many recommendations to improve health care access and quality for individuals with ID/DD:

1. Increase health care professionals' and staff members' knowledge and experience
2. Expand residential staff members' and care providers' knowledge
3. Increase patients' self-determination
4. Provide formal care coordination
5. Improve reimbursement rates

ADDITIONAL KEY INFORMANT FINDINGS

Summary of State Legislator Interviews

Respondents lacked knowledge of and revealed the need for information on the medical needs of individuals with intellectual and/or developmental disabilities (ID/DD). Some demonstrated assumptions about the medical needs of the ID/DD population based on the general public's medical needs. For instance, many identified the shortage of and access to primary care physicians (PCPs) faced by the general population and believed the impact of the shortage would be far greater for individuals with ID/DD.

Although the respondents served on state health care committees, they reported that currently no ID/DD medical issues or policies are before their committees. Furthermore, some reported that even when Massachusetts' legislators were designing our current health care reform policy, health care issues that pertain directly to patients with disabilities were not included on the policy agenda.

Summary of Health Insurance Provider Interviews

Most insurance providers had limited knowledge of the health barriers and challenges patients with ID/DD experience when accessing medical care. Providers who had some knowledge attributed it either to their professional clinical practice or to their involvement in professional networks. In addition, most insurance representatives reported they do not collect data on the specific medical needs of the ID/DD population.

Although respondents had limited knowledge about the direct needs of patients with ID/DD, most stated — based upon their own practical experiences — that the complex medical needs

of this population warrant care coordination or a consumer advocate. Furthermore, many insurance respondents highlighted a finding reported in the insurance section of this report: health care professionals think reimbursement rates are too low.

PROJECT TEAM'S RECOMMENDATIONS

There are several steps between the identification of health care barriers through research and the successful removal of such barriers. Our recommendations are the first step in the process. In the previous sections, we identified multiple health care barriers, salient issues of concern, and recommendations proposed by self-advocates (adults with ID/DD), parents/guardians, and community support and health care professionals. The focus group and health care professional key informant respondents' and The Arc of Massachusetts Health Care Steering Committee members' experiences and recommendations were taken into substantial consideration when developing these policy recommendations. However, we plan to pursue a further dialogue with allies and stakeholders to develop an effective strategy for change.

To address the health care barriers, the Project Team proposes the following six recommendations⁷:

1. *Develop and implement a robust educational program for health care professionals*
2. *Reduce reimbursement barriers of health care professionals and community support staff*
3. *Improve access to high-quality health care at medical practices and hospitals*
4. *Develop and provide formal care coordination for adults with ID/DD*
5. *Develop and implement a robust training program for individuals with disabilities, families, community support professionals, and volunteers*
6. *Conduct additional research*

FULL REPORT

The full report will be available through and posted on The Arc of Massachusetts' web site: www.arcmass.org

To go directly to the report, click on the following links on The Arc's main web page: *Community Services* followed by *Health and Wellness Resources*.

⁷ The recommendations are further discussed in the *Project Team's Recommendations and Discussion* section of the full report.

INTRODUCTION

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

– Reverend Dr. Martin Luther King, Jr.

In 2002, Americans with disabilities accounted for 51.2 million individuals or 20% of the population of the United States (Office of Minority Health and Health Disparities, 2007; Steinmetz, 2006; U.S. Census Bureau, 2006). That figure includes a wide variety of individuals from various demographic backgrounds and with a range of disabilities. It is estimated that seven million individuals or 3% of the population have an intellectual and/or developmental disability (Ouellette-Kuntz, 2005; The President’s Committee for People with Intellectual Disabilities, 2007). An intellectual disability (ID), sometimes referred to as mental retardation, is defined as “significant limitations both in intellectual functioning and in adaptive behavior” (American Association on Intellectual and Developmental Disabilities, n.d.), and it originates before age 18. The term mental retardation is no longer used professionally due to the stigma associated with it. A developmental disability (DD) is defined as mental and/or physical “impairments” affecting daily functioning in at least three or more areas, such as self-care, expressive language, and mobility (Centers for Disease Control and Prevention, October 2004). DD manifests before age 22 and includes different forms, such as autism and cerebral palsy.

Today, more and more individuals with intellectual and/or developmental disabilities (ID/DD), even those with complex medical needs, are reaching old age and residing in various community settings (Braddock, Emerson, Felce, Stancliffe, 2001; Crowley, & O’Malley, 2006; Hayden, Kim, & DePaepe, 2005; Horwitz, Kerker, Owens, Zigler, 2000). The movement from institutional to community-based settings over the past four decades has been successful in terms of integration and providing services in least restrictive settings. However, there has been less focus on the health status of this population, causing their medical care needs to be insufficiently addressed (Havercamp, Scandlin, & Roth, 2004; Hayden et al., 2005; Horwitz et al., 2000). Institutional settings utilized on-site health care professionals who specialized in treating this population. The costs in institutional settings are significant because health care professionals treat smaller caseloads. Individuals within those settings tend to utilize medical services more frequently (Hayden et al., 2005). Community-based services reflect cost savings for states; however, in order to improve health care of individuals with ID/DD in the community, health care professionals need training, experience, and preparation to properly treat this population.

Health disparities are a salient issue affecting many individuals with ID/DD (Office of the Surgeon General, 2002). Health disparities, also termed health care inequalities, are defined by the health outcomes or differences between specific populations, such as disability, gender, or racial/ethnic groups. The health determinants of individuals with disabilities include not only health care access, but also their environment, genetics, and behaviors and socioeconomic and racial/ethnic status (Bachman, Tobias, Master, Scavron, & Tiernery, 2008; Drum, Krahn, Culley, & Hammond, 2005; Krahn, Hammond, & Turner, 2006). Krahn et al. (2006) reported other research findings in ID health disparities: quality of life, morbidity, and mortality. *Healthy People 2010* (U.S. Department of Health and Human Services [USDHHS], 2000) set a general goal of eliminating health disparities for individuals with disabilities; however, the health of individuals with DD was not specifically addressed due to the lack of sufficient data on this population (Havercamp et al., 2004).

The accommodation for the ID/DD population is often overlooked as health systems become more complex and insulated (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, & Maisels, 2006; Havercamp et al., 2004). The U.S. Surgeon General's Report on *Health Disparities and Mental Retardation* (Office of the Surgeon General, 2002) highlighted the huge inadequacies in meeting this population's health care needs. One major concern is the shortage of qualified, trained health care professionals in the community who are experienced in caring for the special medical and mental health care needs of this population (Special Olympics, Inc., 2005; Hayden et al., 2005; Krahn et al., 2006). Individuals who live in rural or inner-city communities face a far greater impact from the absence of skilled health care professionals because, among other reasons, health providers are difficult to recruit to those areas (Iezzoni, Killeen, & O'Day, 2006; Reichard, Sacco, & Turnbull, III, 2004).

Because they tend to have lower socioeconomic status, individuals with disabilities have a higher chance of being insured by public coverage, such as Medicaid (Bachman et al., 2008; Drainoni, et al., 2006; Ellwood & Kell, 2003; Havercamp et al., 2004). Research indicates many health care professionals do not accept Medicaid or choose to limit the size of their Medicaid patient load due to the concern of (a) extra time required, including administrative, to work with the population and (b) inadequate compensation reflected in low reimbursement rates (Harder + Company Community Research, 2008; Havercamp et al., 2004; Reichard et al., 2004). In turn, the search to obtain a primary care physician (PCP) is further compounded for individuals insured by Medicaid as compared with those insured by private coverage (Havercamp et al., 2004; Iezzoni et al., 2006).

Several papers and research efforts since 2000 (Braden, 2002; Fenton, Hood, Holder, May, Jr, & Mouradian, 2003; Fisher, 2004; Horwitz et al., 2000; Krahn et al., 2006; Lewis, Lewis, Leake, King, & Lindemann, 2002; O'Day, Killeen, Sutton, & Iezzoni, 2005; Office of the Surgeon General, 2005) have identified the following additional obstacles and disability health disparities:

- poorer health; higher rates of preventable mortality, co-morbidity, and chronic conditions; and less access to preventative care and health promotion than the general population;
- serious inadequacies in mental and oral health services; breast, cervical, and testicular cancer screenings; and immunization updates;
- limited time during doctors' visits make it difficult to address communication issues and cultural and language barriers and review complex medical concerns;
- cognitive challenges in understanding, recognizing, or communicating their own health problems and adhering to treatments;
- mobility problems, social barriers, and societal misunderstanding and misconceptions;
- financial barriers, even experienced by those who are insured, prevent this population from receiving medical services and prescriptions;
- physical impairments require the need for adaptations;
- insufficient health care provider incentives to ensure the health of this population; and
- lack of research related to the health care needs of this population.

The landmark Americans with Disabilities Act (1990) sought to increase opportunities for individuals with disabilities through the elimination of discrimination and improvement of accommodations (Drainoni et al., 2006); however, there were limited efforts to safeguard the health care of this population. It is unethical for this population *not* to receive the primary health care services offered to all others through the service delivery system. It could also prove to be increasingly costly as there is an aging population of individuals with ID/DD with

many chronic illnesses and many individuals who are forced to access medical services through emergency room settings (Harder + Company Community Research, 2008). Our failure to identify problems early and the poor management of chronic illnesses may increase our overall health care costs.

Despite recently published reports and articles, there is little research assessing whether this population is receiving quality health care (Horwitz et al., 2000). Even with national findings (USDHHS, 2000), most state and local reports on health care access do not track data for individuals with ID/DD (see Brawarsky, Brooks, Mitra, & Chung, 2001).

The purpose of this study was to assess the quality of health care services received in the community by adults with ID/DD in Massachusetts. This report summarizes the year one findings and recommendations of the Project (2007-2008).

METHODS

This study utilized multiple data collection strategies in 2007 and 2008 (focus groups, informant interviews, and on-line surveys) to obtain the varied perspectives of adults with intellectual and/or developmental disabilities (ID/DD) and their parents/guardians, community support professionals, physicians, nurses, other health care professionals, health insurance providers, and state legislators. This enabled the Project to reach a broad and diverse group of respondents in Boston, the greater metropolitan area, and western Massachusetts and to accommodate varying scheduling, communication, and accessibility needs.

Focus Groups

Extensive outreach was undertaken by the Project Director and staff to recruit focus group participants. A majority of participants were recruited through availability and snowball sampling methods. Staff created a recruitment flyer, posted information on The Arc of Massachusetts' web site and in the Arc's quarterly newsletter (mail); personally contacted over 40 disability and community agencies and organizations; and attended meetings of various local community groups, including the Haitian American Public Health Initiatives, Inc. and the Latin American Health Institute, to provide information about The Arc of Massachusetts' Health Care Project and to enlist support and participation.

A total of 10 focus groups were conducted:

1. Three groups in Boston, including two groups from specific minority populations.
2. Six groups in the suburbs or cities in the Metropolitan area, including individuals targeted in Concord, Needham, Reading, and Brockton.
3. One group in Springfield, including individuals from rural settings.

The focus groups primarily targeted adults with ID/DD or families. Two groups were comprised of adults with ID/DD (self-advocates); three groups were comprised of parents/guardians of adults with ID/DD; four groups were comprised of community support professionals (which included mid-level managers/senior staff members, nurses, and state agency personnel); and one group was comprised of a mix of parents/guardians and community support professionals. A total of 18 self-advocates, 41 parents/guardians, and 57 community support professionals participated in the focus groups. Background characteristics of the focus group participants are summarized in Appendixes A, B, and C.

This study received approval from Massachusetts' Department of Mental Retardation's Research Review Committee. Participants signed informed consent forms to partake in the focus group discussion. All self-advocate participants were their own guardian. Self-advocate and parent/guardian participants received a stipend of \$50 for participation, and transportation expenses were reimbursed.

A series of open-ended questions were developed by Project staff to facilitate discussion in the focus group meetings. These questions were developed based upon review of key themes identified in related research and upon suggestions of The Arc of Massachusetts' Health Care Steering Committee members (including family members and health care professionals). Questions elicited participants' personal experiences, perspectives, and recommendations

about health care access and quality; specific questions varied somewhat for the three types of focus groups conducted (self-advocate, parent/guardian, and community support professional). See Appendixes D, E, and F for the three Focus Group Guides.

Focus groups were primarily conducted by the Health Care Project Director and Research Assistant, one facilitating the focus group discussion and the other serving as note taker. Focus group sessions were typically one and a half hours in length. Two of the three parent/guardian focus groups were primarily conducted with individuals who were Latino/a and Haitian to obtain perspectives of family members from diverse ethnic and cultural groups. The focus group with Latino/a parents or guardians was conducted simultaneously in English and Spanish with the assistance of a translator. The same was true with the Haitian parents/guardians, for whom a Haitian Creole translator provided assistance.

Focus group sessions were audio-taped (upon permission) and transcribed. Qualitative analysis and coding of transcript data was undertaken by the Project team of three researchers (Project Director, Research Assistant, and Senior Research Advisor) and involved both independent and joint review of transcript data, reconciliation of coding discrepancies, and revised analyses. Key themes were identified for each grouping.

Informant Interviews

The goal was to obtain information from key informants (health care professionals, health insurance providers, and state legislators) about their knowledge, experience, and recommendations about health care quality and access for adults with ID/DD. The Project Director and staff engaged in various targeted outreach strategies to organizations and agencies to recruit interview participants, including (a) sending project information to a randomly selected sample of members of the Massachusetts Board of Registration in Medicine and to professionals listed in the New England INDEX Physician Search; (b) outreach to various community and health agencies and health care professional groups; (c) personal visits to the offices of seven state senators and representatives; and (d) contact and follow-up with eight public and private health insurance companies.

The individual informant interviews were primarily conducted by the Project Director via telephone or e-mail in order to accommodate the time and scheduling needs of these respondents. One interview was completed face-to-face. Interviews with 26 health care professionals, six public and private health insurance company representatives, and five state legislators representing different health care committees were completed. The health care professional respondents include primary care physicians, pediatricians, neurologists, internists, family nurse practitioners, registered nurses, dentists, allergist, orthopedist, gynecologist, psychiatrist, and other health care administrators. The health care professionals' practice experience with the ID/DD population ranged from none to extensive experience.

Interview questions were developed by Project staff, based upon review of prior research and by recommendations from The Arc of Massachusetts' Health Care Steering Committee. Separate interview guides were developed for the three types of key informants, tapping into topics and issues most relevant to their specific areas of expertise. See Appendixes G, H, and I for specific interview guides for health care professionals, state legislators, and health insurance companies.

Interviews were audio-recorded (upon permission) and professionally transcribed. Qualitative analysis and coding of interview data was undertaken by the Project Research Team, and involved both independent and joint review of interview data, reconciliation of coding discrepancies, and revised analyses. Key themes were identified for the health care professional informant groups.

On-Line Surveys

An on-line survey option was developed and posted on The Arc of Massachusetts' web site in order to obtain additional perspectives of self-advocates, parents/guardians, and community support professionals who did not participate in the focus groups. A brief set of open-ended questions were included in the on-line surveys, similar to the focus group questions. On-line surveys were completed by eight self-advocates, 35 parents/guardians, and 41 community support professionals. Survey responses were reviewed by the Research Team and incorporated in the overall analysis, particularly when additional issues or themes were identified. See Appendixes J, K, and L for on-line survey guides.

PROJECT FINDINGS

Across focus groups and health care professional informant interviews, respondents identified seven key, salient themes: (a) knowledge, (b) communication, (c) quality, (d) access, (e) insurance, (f) care coordination, and (g) recommendations. Key issues and concerns under each theme were also identified. The state legislator and insurance provider findings were not included within the following seven salient themes because their experiences and knowledge of health care needs and barriers for the intellectual and/or developmental disability (ID/DD) population were very limited. However, missing pieces were discovered and some of their shared responses are summarized in the section on Additional Key Informant Findings.

I. KNOWLEDGE

Health care professionals lack sufficient knowledge about how to care for patients with ID/DD. Furthermore, they lack knowledge about the specific health care needs of patients who do not reflect the “typical” patient. The most salient theme across all focus groups⁸ and health care professionals (through interviews) was lack of training and exposure. The finding that health care professionals do not have adequate training and experience connected to a second theme: the need for parents/guardians to educate health care professionals during medical visits. In addition, community support and health care professional respondents identified insufficient training of residential staff as a barrier to patients’ medical care.

Health Care Professionals Lack Sufficient Training and Exposure

Self-advocates and parents/guardians reported that health care professionals who lack sufficient training in ID/DD are ill equipped to deal with the specific medical needs of patients. For these groups, health care professionals who lacked training were considered not “sensitized” and were thought to be incapable of properly completing physical examinations.

Sometimes, they [health care professionals] can’t deal with people with disabilities and that’s very sad. (Self-Advocate)

...they’re [health care professionals] not sensitized to this population, nor do they have education in this, or training in how to deal with this population. (Parent/Guardian)

He’s [internist] a real nice guy, but I don’t think he does such a great job. He never puts my son on the table. When I go to the doctor, they say, Get undressed, [and] he never does that, ever [with my son]. He [internist] just kind of does his vitals and asks me question[s], or my husband questions, but he doesn’t give him a really good physical. I don’t think he really knows what to do. (Parent/Guardian)

Health care professionals’ lack of exposure or sensitivity to the health care needs of patients with ID/DD led to inappropriate labeling and some misdiagnoses.

⁸ Groups include self-advocates, parents/guardians, and community support professionals.

They [health care professionals] label our children...what they don't know is they are also human beings and they have the same rights...[as] other children...."
(Parent/Guardian)

He [doctor] gave her... medication for seizures when she [her daughter] doesn't have... seizure[s]...And she [the mother] said, My daughter doesn't have seizures. So the doctor is telling her, Yes, she does. She has Down's syndrome. She has seizures. They want to give her medication for seizures when she knows her daughter doesn't have ... [them]. (Parent/Guardian)

Parents/Guardians Serve as Educators

Parents/guardians who accompanied their adult sons or daughters to medical appointments sometimes acted as liaisons and educators. Across parent/guardian groups, respondents reported that they have provided health care professionals with particular strategies and interventions. Specifically, parents/guardians had assisted doctors when performing medical procedures, provided recommendations for additional care, and suggested better ways to communicate with patients.

You're educating the staff as well as the medical profession and everybody else.
(Parent/Guardian)

I bring pictures; I am training him [the doctor]. (Parent/Guardian)

Residential Staff Members Lack of Training and Experience

Some health care and community support professionals also reported that residential staff members lack training regarding the health needs of patients with ID/DD. Residential staff members who lack training in patients' health care needs were reported as those who may not be able to properly identify changes in patients' health status.

Depending on the education of the person [staff] that you're communicating with, it varies with which response you get from that person... [who] you're reporting.... Whether they will dismiss your reports of what they're [the patient is] doing as [and state] Oh, that's [a] behavior. They always do that. And [then staff will] not look any further into it. (Community Support Professional)

Residential folks often send in someone who doesn't know the patient well, they don't know the history, they don't know if this person has...X, Y, Z; they don't bring their forms...They're there as a driver and that's it. So you get an individual who may or may not be able to contribute to their own healthcare assessments. And then you have a staff person that's responsible for that individual who cannot contribute to the health assessment. (Health Care Professional)

In addition, health care and community support professionals reported that lack of training led to erroneous or poor care of patients.

I've certainly alluded to it before; there are group homes [with] staff that really don't have training. They get med[ical] training that is very basic, maybe 2-3 hours, on how to read a prescription and basics on how to make sure they're giving the right medications, but there is little oversight to make sure they're doing what they've learned. So frequently, I have been called by a group home [staff member] to say that they just realized that they been giving double the dose of the medication for the past week or month. I had one [instance] that was 6 months. (Health Care Professional)

II. COMMUNICATION

The communication skills of health care professionals, self-advocates, parents/guardians, and community support professionals play a significant role in how self-advocates access medical care. Across groups, respondents highlighted the interactions that have resulted in a lack of communication. Respondents identified three main themes that created a lack of communication between groups: (a) how groups communicate with one another, (b) how language barriers prevent clear communication between groups, and (c) how information is shared. Although the groups mainly focused on situations that stemmed from a lack of communication, positive experiences were also shared. Respondents with positive experiences reported specific strategies that helped to facilitate better communication between groups.

Lack of Direct Communication with Health Care Professionals

Health care professionals make assumptions about patients' abilities to communicate. These assumptions result in a lack of direct communication between health care professionals and patients. All self-advocate and parent/guardian focus groups and some community support and health care professional respondents reported that health care professionals often direct communication to the person who accompanies patients to medical appointments.

Self-advocate and community support professional respondents reported that health care professionals assume that patients do not have the intellectual skills to participate in their medical appointments.

They figure I can't talk, I can't write. So they look at the other person and they shouldn't because I'm just like everyone else in this room. (Self-Advocate)

They [medical staff at hospital] asked my friend, what's her name? I mean, they didn't ask me. I'm my own guardian. No one's my guardian. (Self-Advocate)

When I bring my clients in, they [medical staff and doctors] talk to me. And I keep trying to refer them back to the person, because it's...their appointment. And they still kind of look at me. (Community Support Professional)

Self-advocates' and community support professionals' accounts were supported by parent/guardian and health care professional respondents. These respondent groups added that although some patients may not understand all aspects of medical visits or may express non-verbal communication, health care professionals should increase their sensitivity and alter

their attitudes towards patients in order to develop protocols that would support direct communication with patients.

...there are issues around communication and attitude on part of the staff. So there is attitudinal access. Do clinicians take the time they need to take to help desensitize these individuals so they will be more active to assess care? Do they take the time needed to communicate issues and to explain what's going on? (Health Care Professional)

I think there's some sensitivity, but it kind of comes around to also they [doctors] really don't know whether they're supposed to talk to you or talk to her [the patient]. And with protocol, they should talk to her first anyway, but sometimes people just kind of sidestep and go right to the parent. (Parent/Guardian)

In addition to negative assumptions, lack of sensitivity, and underdeveloped protocols about communication, a good number of respondents reported that health care professionals need to provide patients with clearer explanations about procedures and not rush through their medical appointments.

One of the things that's difficult with my son is that you have to ask a question. And then you have to pause, because his receptive language is just really difficult. So a lot of people don't wait for the pause. (Parent/Guardian)

Lack of Communication Due to Language Barriers

All parent/guardian and four community support professional focus group and some health care professional interview respondents reported language barriers as a reason for the lack of communication experienced. Language barriers stem from a lack of available interpreters and translators and appropriate means of communicating with patients.

But for the world of developmental disabilities, there is no translation. ...the way that I've seen the interactions, awful things — children crawling away, underneath tables, and security coming in and putting hands on them, to try to manage them, to keep them from running away. (Parent/Guardian)

Across parent/guardian respondents, families reported they had a difficult time finding interpreters and translators as well as individuals who could communicate with patients who expressed non-verbal communication.

With my family, when I call to make an appointment for him [son]... the secretary of the doctor only speak[s] English. I have to find an interpreter to be able to speak with her. ...in the hospital where I'm going now, it takes a lot of time to find an interpreter. (Parent/Guardian)

Sometimes you go to an appointment and the person [interpreter] cannot translate your emotions as a parent. Emotions are a big part. (Parent/Guardian)

Some parents/guardians and community support and health care professionals reported residential staff members often did not speak the primary language of verbal residents. This language barrier created concern among health care professionals about the quality of care

patients might receive if left unsupervised with staff who cannot speak the primary language of verbal residents and others.

That's my big problem because... if the house manager... doesn't go, [then] these other people that work in the [group] homes...do not fully understand a lot of things.... What happens when I'm not around? What's going to happen to her? (Parent/Guardian)

It's an obstacle for a lot of staff. English as a Second Language is an issue. (Community Support Professional)

Lack of Information Sharing

Some community support and health care professional respondents reported that information sharing can be challenging across providers and systems. Information sharing was hindered by two main sources: insufficient staffing and legal restrictions to health care records.

You run into different barriers in communicating with different agencies, with other healthcare professionals, with providers, with residential staff, [and] day staff. ...it's all very variable of what type of response you get with different situations. (Community Support Professional)

Some of the nurses in the community support professional focus groups and some health care professional interviewees identified barriers to information sharing when residential settings had three primary characteristics: (a) house managers who did not fully understand the need to communicate across systems, (b) group homes that were understaffed, and (c) support staff who lacked training.

There [are] some residential managers or supervisors that want to hold on to the control and not share information as well. Don't ask me why, it doesn't make any sense to me. But ... a couple of different supervisors, it's a constant battle for me to get the information. (Community Support Professional)

The turnover rate is very high in group homes. Staff members are not trained in a health care background or the population. They are not familiar with ID/DD and they simply don't have the skills to bring to the table. Staff [members] need to be brought up to speed on these issues as well as how to advocate effectively. (Health Care Professional)

Community support professionals seemed frustrated by their inability to access patient information due to legal restrictions.

The hospitals don't call me. Doctors don't call me. They automatically call the guardian. When they have that piece of paper, I am not legally connected to this person anyway. So they're not going to talk to me. (Community Support Professional)

Positive Experiences

A lack of communication was a major finding; however, some self-advocate and community support and health care professional respondents shared several instances in which they had positive communication experiences. Positive care was experienced when health care professionals developed a good rapport with patients and utilized strategic actions to facilitate

communication. Self-advocates seemed to have positive experiences when health care professionals talked to them before beginning medical procedures. When health care professionals gave clear and specific instructions during medical appointments, self-advocates felt as if health care professionals were communicating well with them.

Before they did anything, they just sat you there and they talked it over. They showed you whatever, and stuff like that. (Self-Advocate)

I ... [do know] one primary care [doctor] who does [talk to the patient] very much. ...he gives her specific attention, but has known her for years, and will sit there and literally just have conversations with her.... (Community Support Professional)

Health care professionals who incorporate strategic communication approaches, such as the use of forms, direct communication with residential staff, and accommodations, into their practices seemed to have positive communication experiences.

Generally, it works fairly well. I have a few patients with autism that come with staff and the group home seems fairly well run and they usually bring forms that reminds me what the med[ication]s are at the house and what needs to be updated. ...I have to write my diagnosis and whether there are any changes in therapy, etc. and that usually works well. (Health Care Professional)

I...flag...them at the beginning of the day. I'll go through my list of patients and I'll say Mr. Smith [is] coming in. You'll probably just get him into the room right away, as he can get a little disruptive in the waiting room and they're pretty good about that. (Health Care Professional)

In addition to health care professionals employing strategic actions to facilitate positive communication, health care professional respondents reported that patients who are accompanied to appointments by parents/guardians have a more productive appointment; parents tended to provide an accurate historical medical record.

III. QUALITY

Appropriate and positive attitudes, interactions, and processes performed by health care professionals and residential staff were essential to receiving high-quality medical care. Across all self-advocate, parent/guardian, and community support professional focus groups, two salient categories were identified: poor and good quality medical care.

Poor Quality Medical Care

Every focus group and members from each grouping⁹ identified different types of negative experiences resulting in poor quality medical care. The five main themes identified were (a) bias about and insensitivity to patients' needs, (b) lengthy waits and rushed medical practice atmosphere, (c) negative impact of quality of care based on patients' behavior, (d) inadequate medical care received by patients, and (e) lack of resources.

⁹ Groupings include all self-advocate, parent/guardian, and community support professional focus groups.

Bias About and Insensitivity to Patients' Needs

All self-advocate and parent/guardian focus groups pinpointed different ways that health care professionals, including office staff, were insensitive to patients' needs. It seemed that some of the poor medical care and attention received was connected with negative attitudes and beliefs about individuals with intellectual and/or developmental disabilities (ID/DD) and their overall health and quality of life.

I get a phone call from her [secretary at the doctor's office] saying pay the \$3,688.99. [And I said,] But I don't have that kind of money. [The Secretary said,] Okay, you're not coming back anymore, you're not coming back. (Self-Advocate)

What I find that is often uncomfortable and awkward is the types of things that they [health care professionals] will talk about in front of him [son] with me. ...his behavior, they will ask me about that— embarrassing for him.... And most of the time, they won't even ask or acknowledge that this may be awkward... [or say] could we do this in a different way? (Parent/Guardian)

I made the mistake of saying that she was at Perkins School for the Blind in a behavioral [program].... So what happened was the nurse and the doctor stood at the door and I held my daughter in my arms, took her temperature, helped with the BP cuff and nobody actually came and touched her. (Parent/Guardian)

Self-advocates' and parents/guardians' accounts were supported by community support professional respondents.

I've met people who have had cataracts that needed to come out. And the doctor didn't see the need, because the person didn't read.... (Community Support Professional)

Lengthy Waits and Rushed Medical Practice Atmosphere

Across all self-advocate and parent/guardian focus groups, lengthy waits and untimely appointments, both in emergency rooms and medical offices, were identified as insensitive and not conducive to patients' medical needs. Irritation arose from some respondents after lengthy waits; some patients walked out of waiting rooms before they were seen by nurses or doctors.

Scheduled appointments, they make you sit there for three or four hours. You should take me at 12:00. Instead, they make you wait four or five hours. They don't care if you die in their waiting room. (Self-Advocate)

...how dare you make this person, who my doctor had already called to say he was coming, make him wait? [The receptionist said,] Well, the emergency room is filled. I said, I don't personally care if it's full. I said, Can you see the behaviors he's having? He is a wreck. So I whispered in his ear, calmed him down, and they saw him right away, but it was a nightmare. (Parent/Guardian)

A good number of respondents felt some patients' medical needs were not fully understood because medical visits were rushed (highlighted previously in communication finding section) and some health care professionals did not take time to build relationships with patients before performing medical procedures. In turn, some respondents were reluctant to schedule future medical visits.

Sometimes when you get to the hospital, you don't even sit down very quick. He is already writing a prescription. (Parent/Guardian)

...how...they interact with her when she's sitting in a chair. I watch everything. So that experience, you're just not in a rush to go...again. So we just pushed that [dental] appointment off a little bit more.... (Parent/Guardian)

Others "pushed back" appointments and went without medical care attention due to the lack of alternative and more comfortable medical procedures and forms of screening.

Negative Impact of Quality of Care Based on Patients' Behavior

Three parent/guardian and four community support professional focus groups pointed out that some health care professionals had negative assumptions about patients with behaviors, did not know how to care for these patients, and/or feared for their safety or that of others.

Some respondents reported that patients were labeled as difficult and sometimes went without needed medical services, e.g. preventative and routine screenings, because of behaviors while others were heavily sedated in order to receive medical care. Some patients were referred to emergency rooms because medical offices were not trained or equipped to work with them.

...we had three week trials for our daughter at Tufts many years ago, and all it was [was] a cleaning, and every time she came in, she was fussing so much, they [dentist] said, she's not cooperating, [and] you'll have to make another appointment. We did that three times in a row. (Parent/Guardian)

...they [health care professionals] will say not cooperative. Re-see in two years. Well okay, so if that keeps going on; and, of course, I've done, in my career, lots of historical eye exam report studies, you can go back, and the person was not cooperative for five of their past visits, which translates into 10 years. (Community Support Professional)

Some respondents stated patients' behaviors were sometimes vital to uncovering and validating a medical condition as well as figuring out the medical problem, especially with patients who were non-verbal. Others questioned if behavioral protocols were available to all health care professionals.

Behavior[al] changes are often overlooked that can indicate [a] health issue i.e. bathroom frequently, fever, increase in aggression and anxiety, pacing, humming, increase [of] injuries. (Community Support Professional)

A few of the respondents reported patients who were prescribed new and different medications aimed at correcting those behaviors.

The medication isn't doing anything at all.... [They keep] putting the dose up and up. All medications, he's been on it. (Parent/Guardian)

Inadequate Medical Care

Across eight focus groups¹⁰, many respondents identified that some patients had received incomplete or inaccurate medical care services. Some patients did not receive “normal, routine” medical exams and timely, proper medical treatment.

The doctor said, well, we can't do any more for her. She needs to go home [Puerto Rico], like to die. ...that's why she made the decision to go to Puerto Rico to take her [daughter] to the church, [so] that she should go there and one of the pastors pray for her and [the pastor] told her to take her [daughter] to the hospital. She had to leave the United States where there is more help here to go to another country to be able to save her daughter. (Parent/Guardian)

So they're [doctors] not really receptive to creative solutions to enhance their care and give extra tests, you know, the regular tests that all of us have as we reach adulthood for preventative care, whether it's bone density or mammogram or colonoscopy or whatever. And I just found that I run into that a lot. (Community Support Professional)

I had a woman who had a heart attack, and the ER made us [wait] in the waiting room for three hours. The woman almost died because of the hospital's neglect. (Community Support Professional)

Some respondents stated that patients did not receive adequate medical care because forms were not filled out properly. Four community support professional focus groups reported the difficulties collecting state mandated medical forms – mainly for individuals living in residential homes – from health care professionals, and one self-advocate group in Boston described their difficulties collecting forms, including those needed for non-medical services.

Oftentimes they [health care professionals] don't want to give us that time that we need in order to have them fill out our forms. There [are] a lot of things that come up in the course of working with a doctor that they need to sort of accommodate our requirements that are caused by the state. A lot of doctors just won't do it. (Community Support Professional)

She [health care professional] never mailed it [transportation form]. She never filled it out and mailed it back. (Self-Advocate)

The lack of appropriate accommodations, such as examination tables that lower to the floor, in medical offices were identified by two parent/guardian groups as poor quality and incomplete medical care for patients.

There's no way for them to weigh my son, they have no idea how much he weighs. There's no way to weigh him. (Parent/Guardian)

¹⁰ The groups include three parent/guardian and four community support professional focus groups and one mixed focus group of community support professionals and parents/guardians.

Improper, speedy hospital discharges was identified by three community support professional focus groups as incomplete and partial medical care. This resulted in problems when (a) discharge summaries and recommendations were not received by those who cared for the patients and (b) in-home supports were not in place. Without notice and by ambulance, some patients were discharged on Friday nights. In these instances, many respondents reported that patients usually returned back to the hospitals' emergency rooms within a short period of time. Sometimes, the discharge summary would order patients to be returned to places, e.g. nursing homes, where they did not reside.

...the doctors get it together and realize there isn't going to be reimbursement for the weekend, so they want them out. ...unprepared and very often they're back in the ER by Saturday.... (Community Support Professional)

I had a client that was in the hospital, admitted. They discharged him, sent him back to the group home one Saturday evening and notified nobody. (Community Support Professional)

Lack of Resources

Across four community support professional focus groups, many respondents identified the lack of available resources of agencies and community programs, e.g. residential, as having an affect on the quality of medical care for those patients who are served by them. Funding seemed to be lacking and resources looked as if they were spread thin and squeezed to fit the needs of all clients.

Some respondents reported residential staffing shortages. Residential managers were sometimes forced to send relief direct care staff and/or fewer staff than needed to medical appointments with patients.

Sometimes it's just about the disability. If a patient is 200 pounds many [health care professionals] will say to the patient, don't take your clothes off for the exam simply because there is only one staff and the [medical] provider doesn't want to lift them. (Community Support Professional)

When I hear about somebody coming out of a psychiatric admission and going back to their psychiatrist, and I hear that they have gone with the relief staff, somebody who's never met that person before, and this person had been hospitalized because they were in crisis, first thing I say is there's something really, really, really wrong with that. And it's not the doctor. So we need to care about the people that we support enough to provide a proper advocate for that person. (Community Support Professional)

After going back and forth with them on several people, now, it came back that the hospital was baffled that we don't have... a nurse in every [group] home. ...it's their perception. Their perception is off. (Community Support Professional)

The lack of resources available at medical offices also affected patients.

...it's true, there's a lot of duplication, there's a lot of that extra work that's often required of a doctor. (Community Support Professional)

If we can't get our own interpreter, we will actually do an appointment without an interpreter. ... [We] absolutely don't want to do it, but we will do it. Our nurse [in our program] does sign, although she's certainly not going to be interpreting. But she can sign, so there [are] aspects. And obviously, our staff has good skills. But that's your lowest bottom. (Community Support Professional)

Good Quality Medical Care

Overall, two self-advocate and three parent/guardian focus groups reported different types of positive experiences resulting in good quality medical care. One main theme emerged: satisfaction with overall practice atmosphere.

Positive Practice Atmosphere

Some of the self-advocate and parent/guardian respondents said they felt welcomed when members from the medical offices treated them with respect. Those health care professionals were identified as “terrific” and “phenomenal.” A few self-advocates reported happiness with their health care professionals, particularly due to the direct communication with and involvement of patients.

He treats me wonderful and everything else. He always controls the paperwork, controls everything. He holds nothing back.... (Self-Advocate)

...they took him for another emergency, everybody was on.... [There was a] ... nurse... [and] two doctors in the room.... And everyone was saying, Sam [alias name], stay here with us. They were wonderful. ... it's who's on duty; it's how busy the ward is.... (Parent/Guardian)

Across two parent/guardian focus groups, some respondents pointed out health care professionals who spent the necessary time during and outside of appointments to attend to their adult sons'/daughters' medical needs. Some respondents reported patients who did not need to be restrained or medicated because they became comfortable with their health care professional. A smaller number of respondents reported some health care professionals were sensitive and displayed patience during medical appointments.

[The doctor] opened the record, and I felt as if there was no one in that waiting room. She proceeded to leaf through the pages and ask us very appropriate questions and was as gentle with him on all his vitals, and I felt I was there to assist, and I literally was there, took it all in as an observer. I would recommend anyone [to] see her, she was phenomenal. I'm just hoping she stays in the area...she is great. (Parent/Guardian)

Many of the parents/guardians took it upon themselves to educate the health care professionals of the need to slowly accumulate themselves to the patient (as previously touched on in the knowledge section), and some reported health care professionals who were receptive to that message.

When I went there [new dental office], I talked with the receptionist. ...I said that two of my sons have special needs. ...that's basically what I told them [receptionist and dentist], ... [that] they're shy, and he [one of my son's] will get real defensive if they [the dentist] do[es]n't explain to him, first, what they're going to do. (Parent/Guardian)

Respondents from two parent/guardian focus groups identified some health care professionals who had accommodated to their adult sons'/daughters' needs. The positive experiences were associated with health care professionals who had flexible appointment times and learned to adjust their practice in order to accommodate patients.

And now she has a new doctor, we've only been going to her for about eight or nine months, but she has been wonderful. She takes Sara [alias name] in right away and there's no lingering. (Parent/Guardian)

Actually, our dentist accommodates us by giving her the first appointment in the morning. He knows [to see her] before anybody else because she would scream [while waiting] anyway. (Parent/Guardian)

...the hospital has been fantastic in how they [have] treated him. ...he had to have anti-seizure [medication], [so] we stayed with him for every minute. Then he had to stay overnight to be prepped for the colonoscopy. They had what they call a sitter so we didn't have to stay all night with him. (Parent/Guardian)

IV. ACCESS

The ability to access timely preventative and as-needed medical services was vital and very important to all groups. Across self-advocate, parent/guardian, and community support professional focus groups and health care professional interviews, respondents reported the barriers faced while attempting to access medical care. The three key categories identified by the respondents were (a) problems finding health care professionals, (b) adults with intellectual and/or developmental disabilities (ID/DD) who continue to remain with their pediatricians, and (c) lengthy waits and delays experienced after locating health care professionals. However, positive experiences of accessing medical services were described by one group (parents/guardians).

Problems Finding Health Care Professionals

One self-advocate, all parent/guardian, and three community support professional focus groups and some health care professional interviewees reported the difficulties of locating health care professionals as a salient barrier when attempting to access medical services. For various reasons, all groups identified health care professionals, including primary care physicians (PCPs) and/or medical care specialists, as difficult and challenging to find, especially since there were only a limited number of adult health care professionals.

...it is a barrier to find a physician for them. If an adult patient decides to move to an adult provider [and]... find internal medicine or family practitioners who have an interest in this population, I have found [that to be] very difficult – in my area at least. (Health Care Professional)

It was very limited what I could find out there, who understood autism and [the] family, the whole dynamic of my family. (Parent/Guardian)

Across focus groups and health care professional interviews, multiple respondents reported difficulties in finding medical and non-medical care specialists, including dentists, gynecologists, mental health specialists, dermatologists, ophthalmologists, sign interpreters,

and language translators. These specialists were even more difficult to find if immediate medical attention was needed. As a result of these difficulties, sometimes timely medical treatment was not available.

Well the huge, the biggest issue, which is obviously no surprise to anybody, is ... [the] issues with mental health – behavioral support – it's just not there. (Health Care Professional)

If I have an adult who has development disabilities and they're not on MassHealth, [then] I have no problem getting referrals to general dentists. I can refer them to Mass. General. But the minute they find out that ... [the patient is insured by] MassHealth, I can't do it. (Health Care Professional)

In addition to the limited number of available health care professionals, other difficulties faced during the search process were identified by many respondents. These barriers related to health care professionals who would not (a) accept MassHealth, (b) work with adult patients with ID/DD, and/or (c) accept new patients into their practice.

[There is a] lack of specialists on the adult level who are comfortable and skilled in treating adults with ID/DD. Pediatricians are trained to work with children with disabilities, but not adults. Some do not want to work with adult medical problems. (Health Care Professional)

To further compound the search, a mix of additional obstacles was faced by many respondents when trying to locate health care professionals. Those barriers included the health care professionals' lack of experience, inflexible appointment times, inaccessible equipment, unfit examination rooms, inaccessible buildings, and/or long travel distances, especially in rural areas. Many were left to negotiate and deal with these access barriers.

I've seen some people with disabilities who've never been examined on a table. They've been examined in their wheelchairs. (Community Support Professional)

Adults with ID/DD Remaining with Their Pediatricians

Due to the shortage of qualified health care professionals who specialize in treating adults with ID/DD, some adults remain with their pediatrician as the only avenue available. Multiple participants from the parent/guardian and community support professional focus groups and some of the health care professional interviewees reported that many adults with ID/DD continue to remain with their pediatricians. One pediatrician reported caring for a patient who was 48 years old.

Some respondents felt comfortable remaining with their pediatricians; however, concerns about getting appropriate, age-related medical care were very apparent. Many respondents raised the question of how and/or when one would transition to adult medical care. Others reported that the transition from pediatric to adult care occurred at later ages, for instance age 27 and 40.

[My son is] twenty-five. I go to neurology and I sit with babies and I'll say to the neurologist, where should we go? [And the neurologist responded,] Really, you can stay here. The problem is he doesn't know where to send us. Who's going to see this kid? He sees...his orthoped, his GI, everything...at Children's Hospital. (Parent/Guardian)

Some community support and health care professional respondents highlighted the consequent problems associated with adults remaining with their pediatric physicians instead of transitioning to health care professionals who specialize in adult medicine, including the (a) lack of knowledge of appropriate preventative tests and screenings for adults and (b) lack of proper training about issues related to aging. Some of the pediatrician respondents acknowledged these issues; however, they were determined to do their best and keep the patient until he/she could locate an adult health care professional.

*[A] male with MR [mental retardation] came in with advanced bowel cancer symptoms. [This was] not discovered or acted upon... Do they see doctors preventatively?
(Community Support Professional)*

*...we get [patients] referred in to us ... Children's Hospital has a huge adult congenital heart team.... And the patients are kept here at Children's because they're following them into their 30s and 40s. It's unrealistic for pediatric dentists, who really specialize in three year olds and six year olds, to see someone who's 40. There are adult problems, adult gum problems. ...if they're Mass Health, I have no one to see them.
(Health Care Professional)*

Lengthy Waits Once Health Care Professionals Were Obtained

After the exhaustive search for a health care professional, many participants across all focus groups¹¹ experienced another obstacle: additional delays. If a health care professional was obtained, many participants described a delay between the date the appointment was scheduled and the actual appointment date. The long waits were partly attributed to the limited number of available health care professionals who were knowledgeable and experienced in ID/DD and adult medicine.

When a patient reaches 18, I [would] love [to] be able to transition them to an adult dentist who sees adults with special needs and takes MassHealth in Massachusetts. And there is absolutely no one that I have, that I can refer them to. I have tried to refer them to Tufts. New England Medical Center has a grant to provide dental care for adults with special needs and there's a one-year waiting list. (Health Care Professional)

Lengthy waits caused concern for many respondents. Some expressed frustration because there was no sympathy expressed from the offices of the health care professionals for those who had to withstand unbearable pain for long periods. Others were worried because the medical care needs were further delayed, causing some to question whether the health condition would worsen or not.

I had severe pain that I woke up four or five times a night for four days in a row. And when I called [the receptionist], I said, I have an emergency wisdom tooth and I found out it's not just a tooth, its part of the actual gum line that's infected as well. ... [I called] some time in June and they wanted me to wait until August 30. (Self-Advocate)

Positive Access Experiences

On the other hand, the parent/guardian focus groups varied slightly from the other groups because they reported some positive experiences while attempting to access care. Across two

¹¹ Groupings include self-advocate, parent/guardian, and community support professional.

parent/guardian focus groups, respondents reported that positive outcomes were associated with (a) parents' doctors who "picked up" sons and daughters during the transition period from pediatric to adult health; (b) the ease of finding doctors due to multiple insurances, including private coverage; (c) the facilities that predominantly worked with individuals with disabilities, such as Tufts; and (d) doctors who somewhat identified with the families' culture, for example health care professionals who were Latino/a.

*Because my husband and I had the same doctor, he was going to take [our son] on, sight unseen. So that worked out fine... [The doctor] found out [about our son being insured by] Medicaid afterwards and [we] kind of...worked out those kinks too.
(Parent/Guardian)*

V. INSURANCE

Insurance coverage alone does not guarantee access to qualified health care professionals and necessary medical services. Insurance barriers were identified across all focus groups. Self-advocates, parents/guardians, and community support professionals revealed two salient concerns: patients experience difficulties accessing medical care due to the differences in types of health insurance coverage and patients experience difficulties obtaining needed medical care services due to the service gaps in health insurance coverage. In addition, health care professional interviewees echoed the shortage of health care professionals and attributed one of the causes to low reimbursement rates. Furthermore, parents/guardians identified their lack of understanding of the insurance system as a key issue.

Shortage of Health Care Professionals Accepting Public Insurance

Adults with intellectual and/or developmental disabilities (ID/DD) and their caregivers or providers have a difficult time locating health care professionals who accept patients insured through public health coverage, such as MassHealth (Medicaid). Respondents across all focus groups struggled to find qualified and knowledgeable health care professionals who accepted new adult patients insured through public coverage.

The problem, too, is that our folks are on MassHealth, and that a lot of the primary care providers that I'm calling aren't taking MassHealth. (Community Support Professional)

I noticed that in most cases, they wouldn't take MassHealth. (Self-Advocate)

Some respondents reported choosing a health care professional based solely on their willingness to accept publicly insured patients. Many of those respondents reported that health care professionals who accepted MassHealth tended to have limited knowledge and experience working with the ID/DD population. The inadequate number of MassHealth health care professionals created additional logistical and geographical obstacles for some respondents.

Some of them said, Yes, I take MassHealth, but I won't take adults. [Others said,] Yes, I take MassHealth, but I only take certain disabilities. (Parent/Guardian)

It's hard to find enough doctors...as well as MassHealth physicians. I searched to find a doctor 40 miles away that, finally, was accepting MassHealth patients. Everybody seems to be maxed out and not accepting MassHealth clients. (Community Support Professional)

Other respondents were left without appropriate and timely specialty medical attention because health care professionals, ones they were referred to or located on their own, would not accept their type of insurance coverage.

...the dermatologist that we had to make an appointment with wouldn't make an appointment because the [reimbursement] rates were too low, they didn't take MassHealth clients. So we [my daughter and I] had to wait another two months with a mole that could have been a melanoma; thankfully it wasn't. (Parent/Guardian)

Some respondents reported that their health care professional had once accepted publicly insured patients, but then suddenly dropped those patients due to dissatisfaction with the insurance process and/or reimbursement rate. In turn, these patients and their families were responsible for beginning the search for and finding another health care professional.

We got a letter one day [from our doctor's office] that ... [stated that they were not taking MassHealth patients any more]. [I] called the doctor, ...[and] said I'm willing to pay for a while until I find somebody else, just keep—[They said,] No, we don't want any part of it. [I said,] Well, does your — [And they said,] No, we don't want any part of it. (Parent/Guardian)

Many community support and health care professional respondents identified the extremely low reimbursement rates set by insurance companies as a key barrier. These respondents said that the ID/DD population requires more in office time; thus, reimbursement rates should be adjusted to reflect the additional time needed to provide appropriate care.

Typically visits [with individuals with ID/DD] are not going to be short. Even the sick visits are much longer than the usual. I think it is true for a lot of physicians that it's not worth it from a time perspective point of view. (Health Care Professional)

...it does take more time. It is more work. And they [health care professionals] probably wouldn't be so averse to it [seeing patients with ID/DD] if they were reimbursed properly for the time it's really going to take. (Community Support Professional)

If the patient is covered by MassHealth, the [dental] reimbursement rates are much lower—about 1/3 to 1/2 lower. (Health Care Professional)

In addition to the extended time needed to properly care for patients during medical appointments, some community support and health care professional respondents reported that caring for patients with ID/DD requires additional administrative time for follow-up or care coordination and time-consuming billing issues: lengthy waits for reimbursement, e.g. up to one year, and difficult and challenging billing processes. These disincentives caused some health care professionals to drop publicly insured patients and others to set caps on the number of patients with ID/DD on their panel.

...some of them, I don't receive payment ever. They don't have the correct family care provider, or for some reason or another, things just don't work out. It's a loss. (Health Care Professional)

Systems started to change and we were demanding more paperwork and he [doctor] wasn't willing to... [do a] new way of ... business. (Community Support Professional)

To provide necessary medical services, a few of the health care professional interviewees – those who were very knowledgeable of the ID/DD population – were creative when it came to coding their performed medical service. This creativity allowed the health care professionals to receive reimbursement for the medical services they felt their patients needed.

...sometimes you have to choose a diagnosis to justify a certain blood draw...it doesn't always fit the paradigm available....For example, for [individuals with] Down syndrome it is very common for them to have hypothyroidism, so it's routine that you check...and it's recommended that you check, a minimal screening of TSH every year. Also it's crucial to check for vitamin B12 because it's pretty common they have deficiency. If Down syndrome is the diagnosis ... [and] the reasoning [for testing] is for TSH or B12, then Medicare wouldn't pay for it because they don't consider Down syndrome a reason to get TSH. I leave in the diagnosis for Down syndrome, but for the TSH I have to put in another reason to get it. Like if they have chronic constipation, I can use constipation as a reason to get the TSH. You can find other diagnosis that the patient might have to justify the TSH. (Health Care Professional)

Lack of Adequate Insurance Coverage

In addition to a deficiency in the number of knowledgeable and appropriate primary care providers, respondents identified several specialty areas that were also deficient: sign interpreters and language translators; nontraditional screening procedures; adaptive equipment; medications; and mental health, dental, ophthalmology, and mammography/gynecological health services. Other insurance constraints revolved around limits on the number of times patients could receive certain medical services within a one year period, for instance it was reported that MassHealth has stringent limits on psychiatric and dental visits in a one year period.

It's unfunded. Medicaid should truly pay for the [sign language] interpreters, because we can't have [health care] access without it. ...it's just a simple reality. (Community Support Professional)

... MassHealth won't pay for [a] CAT scan if a person is unable to go through with a mammogram. (Community Support Professional)

I have had three cases of breast cancer and one case of rectal cancer in the past year because the persons were afraid of or unable to complete a "traditional" screening and MassHealth would not pay for other screening. (Community Support Professional)

Because of gaps in coverage, some individuals and families were forced in to difficult financial constraints. One self-advocate and all parent/guardian focus groups identified costly co-pays and/or out-of-pocket expenses as a significant problem. In turn, some of the adults with ID/DD went without needed medical services.

[I am] not going to have [cataract] surgery because [I] can't afford it. (Self-Advocate)

...it's our wages. ...I'm going to give ... [a psychiatrist] \$150 dollars, and then ... pay for the medicine too? (Parent/Guardian)

Lack of Consumer Knowledge of Insurance System

Some parent/guardian respondents reported a lack of understanding of the insurance system as a major barrier. They reported facing many difficulties as they navigated the insurance system. Moreover, some respondents felt stigmatized by difficulties experienced using public health insurance.

The [insurance] conversation makes my head spin. (Parent/Guardian)

...if you have private insurance and you pay for the insurance, [does] that means the doctor would take care of you better [when insured by private coverage rather] than having MassHealth or having free care? (Parent/Guardian)

VI. CARE COORDINATION

Care coordination is not a standard practice for patients with intellectual and/or developmental disabilities (ID/DD). Although parent/guardian and community support and health care professional respondents had varying definitions for care coordination, they all felt as if care coordination was lacking. For some participants, care coordination was about formal processes that helped patients navigate the health care system. For others, care coordination involved informal systems or individuals who stepped in from time to time to facilitate connections between health care providers and patients. Regardless of the formal or informal attributes of care coordination, it was noted by many respondents that the complex nature of the health care needs of patients with ID/DD warrants a more sophisticated level of care. In addition, the health care professional interviewees identified good models of care coordination.

Informal Care Coordination

Although self-advocates were not able to identify professional components of care coordination, they revealed informal practices they sometimes sought in order to receive help with their medical needs. Most often, self-advocates asked for or received help from family members, neighbors, friends, and/or service coordinators. These individuals performed various tasks: (a) paying medical bills, (b) making appointments, and (c) filling prescriptions. In one instance, a self-advocate described how a neighbor took matters into her own hands and worked out a solution to his medical needs.

Yeah, Mike's [alias name] wife. These are the people that lived on the second floor under us ... And when she heard about this, she kissed me because I'm like family to her. And so she took—She says, "Martin [alias name], stay, and I'll take you. She took me down herself, and not only that, they took care of the problem that day. (Self-Advocate)

Parents/guardians commented that when their adult son or daughter received medical care from pediatric health care professionals, care was almost always coordinated. However, since

transitioning from pediatric to adult care, all parent/guardian focus groups reported that they experienced a fragmented system of care in the adult medical care system.

There's a care coordinator in the [pediatric] office[s]. ...I think that makes a huge difference in the kind of care that kids get, and I don't see why it wouldn't work for adults, for this population." (Parent/Guardian)

I think the biggest problem for us, for the parents especially as we're getting older, is the system is so fragmented, the adult system. We were used to a system where the issues were coordinated by the medical profession and you could speak to a team, everything was a team effort. And suddenly, they reach the adult world and it's not. It's not, it's an individualized thing. So, I think that the thing we have to really strive for...is to almost force the doctors to work as a team. Now, it took us quite a few years to do that, but we got a team of people that talk to each other. (Parent/Guardian)

Parents/guardians who found a missing or fragmented system of care in the adult medical care system stepped in to coordinate their adult son's or daughter's medical care. Parents/guardians reported juggling phone calls and various medical appointments.

...I think I have three or four envelopes just on maintaining it [insurance applications and bills], plus the yearly physicals, the yearly dental visit, [there are] so many things in managed care. (Parent/Guardian)

Balancing a patient's medical needs is a very difficult task. As such, parents/guardians who assume the role of care coordinator can sometimes feel overwhelmed.

...in the meantime, I'm a parent. I have an allergist, a dermatologist, a gastroenterologist, a[n] urologist, a pediatrician. I don't know if there's something I left out— a psychiatrist and a dentist. And I have respite staff I'm managing at home. ... And I am looking for my fifth behavioral consultant. (Parent/Guardian)

The Need for Formal Care Coordination

Three community support professional focus groups and some health care professional interviewees also expressed a need for care coordination. Patients who do not have an individual to act as their care coordinator sometimes missed scheduled appointments or arrived for appointments that had to be rescheduled due to a breakdown in communication between providers.

Another story is about a situation with [a] residential provider who set up [a] psychiatric meeting but left [the] service coordinator (regional Department of Mental Retardation [DMR] case manager) out of loop, which meant a second meeting with consult[ants] had to be set up since all information hadn't been gathered (day, residential, and family); this type of thing does happen due to staff from home or day program[s] holding back information and not coordinating. (Community Support Professional)

We just want to make sure they [patients] can keep their appointments.... And coordinate their care with other specialists. (Health Care Professional)

In situations where community support or health care professionals played the role of care coordinator, they found themselves assuming the role of detective, advocate, educator, and/or

liaison. In some instances, these professionals had to demand services from different providers.

You have to advocate for them. You sometimes even have to fight for them, basically. (Community Support Professional)

Many health care professional interviewees stated the need for care coordination because they did not have the time to perform the service. Care coordinators were described as persistent and consistent and viewed as the crucial piece needed in the adult medical world to reinforce coordinating care – e.g. follow-up on referrals, prescriptions, and lab work – for patients with ID/DD living with their families and in group homes.

I think sometimes when you have someone, when you have a family that is not very involved whether because of problems in the family or because, you know, the patient is older and the parents have passed on, or because the patient has been institutionalized, [then] there is usually less than adequate follow-up in the patients... [They] need support from others in order to be able to carry out...recommendations with another physician. (Health Care Professional)

Strategies for Care Coordination

In the health care professional interviews, some respondents mentioned other programs that used good models that emphasized care coordination.

...Commonwealth Care Alliance has been designated through Medicare Part D to be a special needs program. This is a specific program whose foundation is care coordination. They can develop networks and either provide the nursing coordination from their own base or they can have health centers or other practitioners work with them to do care coordination. (Health Care Professional)

Personally I use [the] volunteer advocacy program [at BMC] and at this point I have an advocate involved with all of my independent patients. I can say to the advocate, can you meet so and so and walk them over to cardiology to see whether they do have an appointment and make sure they get in and all that stuff. (Health Care Professional)

A few of the health care professional interviewees who were familiar with the challenges patients and families faced as they entered or continued in the adult medical care world implemented their own systems of care coordination. In some instances, health care professionals assigned a staff member to act as the liaison between patients and other providers.

To be honest, nothing worked well until I had our care coordinator because adult doctors and pediatricians are never trained; we're never given any information on what's available as far as ...the care coordination [piece].... The parents will come to me and say what do I do? They'll say I don't understand what I have to do next. That is what very much triggered me to hire our care coordinator to have her become a specialist in all these areas to help the families. This has proven to be extremely helpful not just to me, but obviously more so [for] the families themselves. (Health Care Professional)

VII. FOCUS GROUP & HEALTH CARE PROFESSIONAL INTERVIEW RESPONDENTS' RECOMMENDATIONS

All focus groups (self-advocate, parent/guardian, community support professional) and many health care professional interviewees offered numerous recommendations to improve health care access and quality for individuals with intellectual and/or developmental disabilities (ID/DD). All respondent groups emphasized the need for knowledgeable and experienced medical staff, offering suggestions about types of training and populations who should receive training. Community support and health care professional respondents also stressed the need to educate residential staff and care providers about the medical needs of individuals with ID/DD. Advocacy by self-advocates about their own health care needs and advocacy by staff on behalf of patients were recommended by self-advocates and community support professionals, respectively. Many health care professional interviewees recommended the need for (a) care coordination as critical to improving health care for people with disabilities¹² and (b) reimbursement rates to reflect the actual time spent providing medical services to the patient population.

Increase Health Care Professionals' Knowledge and Experience

All focus group and some health care professional interview respondents stressed the need for specialized training and exposure of doctors, nurses, and other medical staff in order to increase the sensitivity and knowledge of health care professionals to the needs of individuals with ID/DD.

Well, I think it's important that they realize the different forms of disabilities that are out there. Like, not just people in wheelchairs, not just people with canes, there's many different types of disabilities out there. (Self-Advocate)

During the training, people going into that field, they should be taught how to deal with people with disabilities through specialty training. They should be well trained. Expose them. Do home visits. Grade you as pass/fail. They would be more sensitive. (Parent/Guardian)

Why can't we make it part [of] – just in tandem with their OSHA training, the diversity training, all this other kind of training – ongoing annual training to help sensitize the ER staff and the doctors to this population? (Parent/Guardian)

Those in the medical care profession need early exposure and more training. For example, DMR has an internship with Simmons College where 6-10 nurses are paired up with area nurses. They are taught how to interact with [the] population. (Health Care Professional)

Self-advocates also recommended that medical staff “know about MassHealth” and “treat us with more respect.”

Parents/guardians recommended that hospitals, particularly emergency rooms, hire staff, nurses, and doctors, “who know how to deal with special needs kids.” Another parent/guardian suggested that medical practices “institute some system to alert their staff” when an individual

¹² Care coordination was also identified by parents/guardians and community support professionals.

with special needs is coming in for medical attention in order to appropriately treat upon arrival to the conclusion of the medical visit.

Community support professional respondents recommended training for all staff members who interact with patients with disabilities.

Everyone needs to be educated, even receptionists in the waiting room.... (Community Support Professional)

In the health care professional interviews, many respondents suggested ways to increase knowledge and experience of health care professionals.

I think we need to be able to set up functional group practices for the multi-disciplinary in our academic centers... we need a group practice that has internal medicines, psychiatry, gynecology, neurology, in the same facility, sharing information and actually being physically near each other, so that we can go talk to the other individuals who are involved in the case. ... They can have in-patient, out-patient, all within the same hospital facility. (Health Care Professional)

It would be nice to provide a setting in which all the services are under one roof and at the same time. So it would be nice to have somebody come in for their Ds [Down syndrome] visit and at the same time be able to have an appointment in the same place with a physical therapist, or a nutritionist, or an ophthalmologist. So if they consolidate all the medical care, the family wouldn't have to make more than one trip. And that's very difficult to organize.... (Health Care Professional)

Expand Residential Staff Members' and Care Providers' Knowledge

Community support and health care professional respondents placed strong emphasis on providing basic training to direct care staff and caregivers about the medical needs and treatment of individuals with ID/DD. Direct care staff and caregiver training needs included how to (a) recognize health symptoms and know when to seek treatment, (b) accompany an individual on a medical appointment, (c) gather information and communicate with health care professionals, and (d) support the patient with decision-making.

Going to a physician's office is a skill set, and should be seen as a higher skill set. ...train people [residential staff] to do it, and what to gather and glean for information. (Community Support Professional)

Don't send people [residential staff] on appointments who aren't trained. Train the staff.... (Community Support Professional)

Increase Self-Determination

Self-advocates stressed the importance of advocating on their own behalf to get the medical help they needed and to make medical decisions. Furthermore, they recommended increasing their access to information about MassHealth and other relevant insurance issues.

I rose above these things because I would not let them decide for me, I decide for myself. (Self-Advocate)

If you don't understand something, that's okay and you have to say, excuse me, you need to slow down and explain better. (Self-Advocate)

Provide Formal Care Coordination

All participant groups¹³ identified the need for patient advocacy and a good number of respondents recommended that patients with ID/DD receive care coordination as a formal service in order to increase access to high-quality medical care. Many community support and some health care professional respondents discussed the need for patient advocacy by staff, particularly on behalf of individuals with severe disabilities, complex medical needs, behavioral problems, or who are non-verbal. They recommended that advocates accompany individuals on appointments, help coordinate care, and be available in hospitals.

Make sure all individuals with severe disabilities including those [who are] non-verbal have someone to advocate for them. [The advocate could be a] nurse or other well trained, informed staff. (Community Support Professional)

I think my patients really like having an advocate. It's just a nice friend they have at the medical center that helps them get to their medical appointments. ...a system like that can be very helpful. ... Where it's difficult to navigate the system, I think it's easier to have that [advocate system]. (Health Care Professional)

Many community support and health care professional respondents recommended formal care coordination for patients with ID/DD. A care coordinator was identified as a person “who has an understanding of [the] medical issues and who... [would] help with the transitioning times from different places, to make sure that all of their needs are met, and that they get the care they need.” Some offered suggestions of who could provide care coordination: nurses, social workers, or case managers.

A lot of our folks have multiple caregivers. They may have a primary care physician (PCP), a neurologist, a psychiatrist and one issue in general in the health care system and more notable with our folks is care coordination. This is a huge issue. Where in fact [if a patient has]... a nurse or NP [nurse practitioner] who's coordinating care, [then] you're likely to get more collaboration and integration; otherwise, it can be very fragmented. (Health Care Professional)

If you could have nurses or NPs really available and accessible to families and to providers, then that would be a tremendous help. Where somebody could help somebody navigate the complex maze of health care and assure early protection, prevention, good intervention, and follow up. That would certainly be a key. And [have] the ability to be available to consult and support primary caregivers. (Health Care Professional)

Some respondents identified care coordination as a way to improve communication between the different health care professionals.

...their [patients with ID/DD] care gets fragmented. ...the right hand doesn't know what the left hand is doing, or the cardiologist doesn't know what the internist is doing. ...the neurologist doesn't know what the cardiologist is doing. So communication between

¹³ Participant groups include self-advocate, parent/guardian, and community support and health care professional.

care providers has to be improved, because the actual patient can't.... They're not [always] an effective advocate for themselves. (Health Care Professional)

There needs to be some better way of communicating between the different services and the doctors than what has been because it's just not working. (Health Care Professional)

Improve Reimbursement Rates

Health care professional interviewees addressed the need to improve the current low reimbursement rate system to reflect the actual time spent providing quality medical care to patients with ID/DD.

Better reimbursement [is needed], so [medical care] providers can spend the time that is needed to serve these patients appropriately. (Health Care Professional)

...the most important thing is that the doctors are...in the community...and able to work with people with ID/DD...and they are paid and supported adequately. (Health Care Professional)

ADDITIONAL KEY INFORMANT FINDINGS

As previously mentioned, the state legislator and health insurance provider interview responses were not included within the above seven salient themes because specific experiences related to the medical needs of individuals with intellectual and/or developmental disabilities (ID/DD) were limited among most of these respondents. In turn, a summary of each informant group is provided.

I. SUMMARY OF STATE LEGISLATOR INTERVIEWS

Most respondents lacked knowledge of and revealed the need for information on the medical needs of individuals with ID/DD. Some demonstrated assumptions about the medical needs of the ID/DD population based on the general public's medical needs. For instance, many identified the shortage of and access to primary care physicians (PCPs) faced by the general population and believed the impact of the shortage would be far greater for individuals with ID/DD. Overall, most reported the need for education on the medical care barriers faced by individuals with ID/DD in the Commonwealth.

...it's the first time that people have been speaking to me. And I've been involved in disability community issues and healthcare for a long time. And no one's really specifically spoken about the healthcare needs of this constituency, and how they're not being met. So I think this is really important, to start this discussion. (State Legislator)

Although the legislator respondents served on state health care committees, they reported that currently no ID/DD medical issues or policies are before their committees. Furthermore, some reported that even when Massachusetts' legislators were designing our current health care reform policy, health care issues that pertain directly to patients with disabilities were not included on the policy agenda.

[After] all this talk about health care reform and the feeling that we really made some major progress, I have never heard of anyone talk about it in terms of people with disabilities...in this building.... (State Legislator)

II. SUMMARY OF HEALTH INSURANCE PROVIDER INTERVIEWS

Most insurance providers had limited knowledge of the health barriers and challenges patients with ID/DD experience when accessing medical care. Providers who had some knowledge of the barriers and challenges faced attributed it either to their professional clinical practice or to their involvement in professional networks. In addition, most insurance representative interviewees reported that they do not collect disability data on their members.

I could never, not being a clinician, I couldn't tell you, differentially, what the services needs are for people with intellectual disabilities, as opposed to other...[disabilities]. (Insurance Representative)

I've heard from people first-hand. And I've heard from their family members. And I've heard from providers who work with them. (Insurance Representative)

Although respondents had limited knowledge about the direct needs of patients with ID/DD, most stated — based upon their own practical experiences — that the complex medical needs of this population warrant care coordination or a consumer advocate.

...there isn't an advocate or someone to assist with the follow-through. (Insurance Representative)

Furthermore, more than half of the insurance respondents highlighted a finding reported in the insurance section of this report: health care professionals think reimbursement rates are too low.

...there's not enough of the extra reimbursement to providers, in general. (Insurance Representative)

PROJECT TEAM'S RECOMMENDATIONS AND DISCUSSION

There are several steps between the identification of health care barriers through research and the successful removal of such barriers. Our recommendations are the first step in the process. They have been vetted with knowledgeable health care professionals and advocates. The experiences shared and the recommendations proposed by the focus group and key informant respondents and Project's Steering Committee members were taken into substantial consideration when developing these policy recommendations.

In order to convert these recommendations into policy or systems changes, activity is needed in the following areas:

1. Review recommendations with stakeholders in the field of health care, which include insurers, hospital and medical systems, medical professional societies, and public sector leadership.
2. Educate and engage individuals with disabilities, family members, professionals in the disability field, and allied groups.
3. Advocate on specific changes in practices, policies, payment systems, or regulations.

The following questions guided the Project Team when developing the recommendations and the six questions will continue to be important in any future systems change activity:

1. Is the recommendation critical to advancing access to high-quality health care services?
2. Does the recommendation have a specific, valued impact or does it have multiple benefits?
3. Will the recommendation require significant restructuring of a system(s), regulation(s), etc.?
4. Is the recommendation related to existing health care reform or other activities?
5. Do and which recommendations leverage additional support through alliances?
6. Do and which recommendations attract the most resistance? What is the basis for the resistance? Is the basis (a) lack of knowledge or education, (b) fear of systemic change and its impact, (c) financial cost, and/or (d) other?

Some of the following recommendations reflect changes in practices, policies, or regulations while others are primarily resource or funding related. A number of recommendations are educational in nature, and some address the need for future research.

The Project Team proposes the following six recommendations:

1. Develop and Implement a Robust Educational Program for Health Care Professionals

- Establish a requirement for a course on intellectual and developmental disabilities (ID/DD) for all health care professionals' registration or licensure. Elements should include an experiential component in working with individuals with disabilities, including those who (a) have ID/DD, (b) exhibit non-verbal communication, (c) display behaviors, and/or (d) are from diverse communities who may or may not speak English as a second language.

- Incorporate training at larger health practices and systems that include (a) exposure to individuals with ID/DD, (b) understanding of where individuals reside and the supports available, (c) understanding of how to communicate with individuals who are non-verbal and/or exhibit behaviors, and (d) interaction with a representative from the community service system (advocacy, provider, or state agency). A state agency, such as the Department of Public Health, MassHealth, or Department of Mental Retardation (DMR), should be tasked to oversee the program with the appropriate allocation of funds.

Discussion: Our recommendations for health care professional education include a change in regulation and practice. Given our findings and research conducted by others, the need for significant education of health care professionals appears to be obvious. However, if health care professionals are not aware or interested in this specific area, then a recommended modification in practice is not likely to result in any change. The corresponding regulatory change connects proposed education to registration requirements. The change is a positive short-term improvement, which would result in an immediate impact.

In far too many medical settings, individuals with disabilities who communicate non-verbally or demonstrate behaviors in the waiting room are seen as a *problem* to health care professionals and receptionists. Without health care professionals' training, exposure (sensitivity), and/or institution of accommodations, individuals with disabilities are seen as *they*. This is an example of discrimination that individuals with disabilities may experience. Additionally, individuals from diverse communities may experience discrimination due to difficulties in communication and/or lack of health care professionals' understanding of cultural values, beliefs, or practices. With education and exposure, health care professionals and other medical staff would have a better understanding of how to serve individuals with disabilities, including those from diverse, multicultural communities.

Three positive voluntary programs that serve as good training models are "Here to Help" at Boston Medical Center (BMC) (Andry, Emmerich, & Cerreto, 2004); "Operation House Call" at The Arc of Greater Boston (2008); and Nurse/Nurse Practitioner Training Module at Simmons College (J. Rico, PhDc, MBA, NP-BC, personal communication, November 23, 2008). These programs have been a positive resource in educating health systems and preparing professionals. Two of these programs have limited funding and reach a small proportion of health care professionals and/or systems. Unfortunately, the programs face the risk of termination due to the lack of funds. In the "Here to Help" program, volunteers provide additional support to individuals with ID/DD when they are admitted or discharged from BMC. "Operation House Call" targets third year medical students in the pediatric rotation at Boston University Medical Center. These medical students hear a lecture on disabilities in the classroom followed by a visit to a family's home in the Greater Boston area. Simmons College, linked with the DMR, a chapter of The Arc, and a school collaborative, provides students opportunities of exposure to individuals with ID/DD in community settings. It is part of their community health rotation.

II. Reduce Reimbursement Barriers of Health Care Professionals and Community Support Staff

- Increase reimbursement (public and private) of health care professionals to reflect the actual time spent providing high-quality medical care to patients with intellectual and/or developmental disabilities (ID/DD). Evaluate and address additional costs for

family/collateral contacts to improve care coordination of patients with ID/DD who are covered by private and/or public insurance.

- Fund Senate 2764 that will properly reimburse community support staff.

Discussion: Addressing reimbursement rates requires collaboration with insurers (both public and private), health care professionals, and medical systems to insure that changes are integrated with existing billing practices and those changes do not create unintended consequences. Additionally, participation is needed to address technical matters, such as the use of certain billing codes and acceptance of those codes by health insurers.

Over the past decade, progress of pediatric care has been demonstrated through the establishment of the *medical home*. Massachusetts Consortium for Children with Special Health Care Needs (2002) defines medical home as “not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner” where partnerships are formed between patients/families and their primary care office. Primary care in a medical home is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” (The National Center of Medical Home Initiative for Children with Special Needs, 2008). (This concept is also related to the following recommendations: access to high-quality of care and care coordination). This progress is reflected in the work around billing codes, which is an ongoing effort for children with special health care needs (Norlin, 2008; The National Center of Medical Home Initiatives for Children with Special Needs, 2007). Professional organizations, including the American Academy of Family Physicians, joined the Patient Centered Primary Care Collaborative (PCPCC) to issue joint principles of the medical home (PCPCC, 2007) and sponsor a conference (PCPCC, 2008). Two examples of codes utilized in pediatric care, which are related to adult medical needs reflected in this report, include (a) prolonged physician services, *not* face-to-face (99358-99359) and (b) prolonged physician services, face-to-face (99354-99357) (Norlin, 2008). Other codes reflect health plan oversight and special evaluations.

Community support professionals play an important role in informal health care coordination and reinforcement of follow through in patients’ health treatment plans. The pay for community support staff has been deflated nationally, which resulted in several organizations pushing for a federal bill (H. R. 1279) to allow additional federal reimbursement to states to raise direct support staff members’ wages (American Network of Community Options and Resources, 2008). As noted in further discussion under the access to high-quality of care and care coordination recommendations, families and community support professionals can play critical roles in assisting individuals with ID/DD to obtain optimal health care. In Massachusetts, timely funding of Senate 2764, which sets forward a rate review process for human services programs, should address this problem (The Arc of Massachusetts, 2008).

III. Improve Access to High-Quality of Care at Medical Practices and Hospitals

- Develop a medical system data collection method on health care needs and status of individuals with intellectual and developmental disabilities (ID/DD).
- Establish safeguards for medical practice and hospitals regarding admission, discharge, and treatment planning for individuals with ID/DD.

- Increase the availability of primary care physicians (PCPs) and other health care professionals through various strategies, including special insurance programs, reimbursement schedules, and outreach.
- Review and enhance (as needed) policies and regulations regarding the availability of translator and interpreter services at hospitals and medical practices. In addition to addressing individuals who do not speak English, establish protocols for individuals who use sign language and nonverbal expressions to communicate.
- Develop a plan to ensure access to assessable equipment or specialized medical techniques/therapies at medical settings.

Discussion: Problems associated with negative quality of care are a concern not only to individuals with ID/DD but also to others. Problems for the general population range from preventing further illness, such as infections in hospitals (Consumers Union, 2008) to improving practices at health settings (Partnership for Health Care Excellence, 2007). Negative consequences are multiplied for individuals with ID/DD who cannot adequately speak up or advocate for their health care needs. However, our study found examples of good quality care, which demonstrates that barriers can be overcome.

Since a system following the health care needs of individuals with ID/DD is missing, there is no way to track the health care barriers preventing high-quality medical care (see Brawarsky et al., 2001; Centers for Disease Control and Prevention, December 2004). There is a need for an “Office of Health Equity” for individuals with disabilities, just as the one proposed for individuals from diverse multicultural communities. Quality of care is a high priority area for action and needs the participation of state agencies, including the Department of Public Health.

As demonstrated in this study, there is a need to safeguard admission, discharge, and treatment planning for individuals who enter medical practices and hospital systems. This includes increasing communication between health care professionals and the involved families and/or community support staff of the patients’ health treatment plans. This recommendation will require further discussion with stakeholders.

There is a need to increase availability of and access to PCPs and other health care professionals. This includes increasing access to psychiatry and follow-up services for individuals insured by MassHealth. Consulting physicians and/or nurse practitioners are needed to educate PCPs and other health care professionals, including dentists, on how to introduce adults with ID/DD into their practice. In some cases, it would be more effective to provide primary care services in the home to individuals with complex medical conditions. This recommendation will require further investigation of accessing certain health care professionals and further exploration with health insurers, systems, and policy makers (see additional research recommendation).

The need to address communication barriers cuts across three important areas: (a) individuals who do not speak English as their primary language, (b) individuals who are deaf, and/or (c) individuals who are nonverbal. This recommendation area requires further discussion with stakeholders.

Special equipment used to conduct tests for individuals in wheelchairs is not available. This issue has been studied in the past at the Department of Public Health and is presently unresolved. One suggested approach is the funding of such equipment at hospitals in different

regions to ensure access for individuals across the state. Specific policy actions for this recommendation will require the involvement of other disability advocacy organizations, state and private health insurers, and health care systems, such as hospitals or public health centers. Although more complicated, a year-long focused dialogue on this issue could result in recommendations implemented over a three year period. Other accommodations, such as scales and desensitizing individuals to their health care professionals at medical visits (with and without utilizing drugs, anesthesia, etc.), are important to include in any meeting discussions in order to execute this recommendation.

IV. Develop and Provide Formal Care Coordination for Adults with ID/DD

- Increase and provide formal care coordination for all adults with intellectual and/or developmental disabilities (ID/DD) through primary care practices, enhanced nursing or social work consultation, and other approaches.
- Increase the effectiveness of informal care coordination performed by individuals with disabilities, family members, and/or surrogates.

Discussion: This story reflects a need to provide formal care coordination. Formal coordinated care should be available within the existing health care system among health care professionals, practices, and hospitals. Such care coordination also includes effective communication to the patient, surrogates, or others who may provide long-term or community support services.

A formal care coordinator should be available for all individuals with disabilities, including those living with families. Formal care coordinators are medical staff, social workers, or other professionals who have several functions:

- navigators of the system,
- educators of health care professionals on disability-related information, including recommendations on how to communicate with and prepare individuals with disabilities for medical appointments or procedures,
- follow-up supporters/reinforcers after patients' medical or home care visits,
- communicators with collateral contacts, and
- patient advocates and liaisons within health systems or with health insurers.

Primary care health professionals (PCPs) can play a key role in care coordination. PCPs (medical doctor, nurse practitioner) need more time to address the entire health plan of individuals with ID/DD. As referenced under the previous reimbursement recommendation section, four professional organizations, including the American Association of Family Physicians (AAFP), have identified the need for a medical home, which would further re-structure medical services to be based around PCPs. They cite the following characteristics (AAFP, 2008): (a) patients have a relationship with a personal physician; (b) practice-based care team takes collective responsibility for the patient's ongoing care, including providing and arranging all the patient's medical care needs; (c) patients can expect care that is coordinated across care settings and disciplines; (d) medical practices measure and improve quality of care as part of daily work flow; (e) patients experience enhanced access and communication; and (f) medical practices use electronic health records (EHR), registries, and other clinical support systems. The Arc of Massachusetts will recommend to The Arc of the U.S. to advocate for this recommendation, and we assume it will reflect a multi-year effort.

There are other means or strategies that reflect good models to ensure that a care coordinator is available to some individuals with ID/DD in Massachusetts. The Commonwealth Care Alliance manages a program that targets individuals with disabilities and special health care needs. It works in partnership with the consumer and PCP to coordinate all appropriate health services (Commonwealth Care Alliance, 2008). The program presently serves only individuals who are eligible for Medicare and Medicaid (MassHealth) concurrently.

Another approach is reflected in a project in Southeastern Massachusetts hosted by the Shriver Clinical Services: "Medical Safeguarding Project." In one Department of Mental Retardation (DMR) region, nurse practitioners work with a consulting doctor to assist community support staff who work with individuals with complex medical needs (A. Blanchet, M.D., personal communication, October 11, 2007).

Both of these approaches (Commonwealth Care Alliance and Medical Safeguarding) operate across medical care systems, individuals and families, and community support systems. They may serve as formal care coordinators and partially play the role of informal care coordinators.

Formal care coordination is not enough; the role of an informal care coordinator is also important because it compliments and reinforces the service provided by a formal care coordinator. The research findings reflect the need to improve informal care coordination, but this recommendation should not detract from the greater need to provide formal care coordination.

Informal care coordinators (adults with disabilities; family members; and/or surrogates, including community support staff and involved neighbors) play a critical role in insuring their own or the patient's health care. This role includes:

- conveying the patients' correct information (reporters of medical histories, health status and symptoms of current illnesses),
- implementing the patients' health treatment plans as suggested by health care professionals, and
- advocating for the patients' best health care treatment.

Patients' health care treatment plans can be reviewed by medical or health care professionals and translated (as needed) to individuals with disabilities, family members, and/or community support staff members. In effective care coordination, there may be overlap between formal and informal care coordinators. This serves to only safeguard patients' health and medical care.

This study specifically pointed out community support staff members' deficiencies regarding their ability to effectively perform this role, so the need to increase their skill and performance as informal care coordinators is apparent (noted under following recommendation section).

Community support professionals should have the responsibility of informally coordinating the care of individuals with disabilities who live in staffed apartments and homes. Policies can be implemented to require *only* program managers and experienced senior support staff members to accompany individuals to medical appointments. Relief staff or improperly trained support staff should not accompany individuals to medical appointments.

Community programs also need staff members to be able to effectively communicate with the individuals they serve and their family members. It is critical to address language and cultural

barriers among support staff members, individuals, and health care professionals. The community support system also needs to address the barriers of patients and families who do not speak English as a primary language or community support staff members who are learning to speak English as a second language.

There is also a need to have consultants available to assist individuals with disabilities, family members, and surrogates (including community support staff and involved neighbors) in the role of informal care coordinators. If the role of formal care coordinators is standardized and made available, then this need may decrease. However, individuals with complex medical conditions may require social work or nurse consultants to provide training on or communication of diagnoses, discharge plans, treatment plans, and other important health related information. The availability of such consultation requires additional funding through MassHealth (Medicaid) or the DMR.

V. Develop and Implement a Robust Training Program for Individuals with Disabilities, Families, Community Support Staff, and Volunteers

- Implement best practice training for community support staff, including how to (a) recognize health symptoms and knowing when to seek treatment, (b) update medical histories, (c) accompany individuals on a medical appointments, (d) gather information and communicate with health care professionals, (e) address behavioral needs at the appointment, (f) support the patient with decision-making, and (g) advocate within the system of care. Identify and disseminate a companion piece that helps community support staff learn their responsibilities, including effective communication.
- Develop a training program for self-advocates (individuals with disabilities), family members, and volunteers that includes (a) effective communication with health care professionals and those involved in support services and (b) advocacy approaches to obtain quality health care. Include training on how to report complaints on medical professionals to the board of registration or complaints on medical systems to management or licensing authorities.
- Create fact sheets to assist individuals with disabilities, community support staff, parents/guardians, and volunteers on preparation for medical visits and practices for positive outcomes after medical visits and/or throughout health care interventions. Please note that the Department of Mental Retardation has developed resources on health promotion and coordination. (Massachusetts Department of Mental Retardation, n.d.).

Discussion: Community support staff members need ongoing training to properly implement both their informal care coordinator and health care supporter roles. Despite good written materials and forms, it has been reported that community support staff members have difficulty completing forms and properly representing individuals' medical needs at appointments.¹⁴ Training, combined with consultation from health care professionals (noted in previous care coordination section), is essential to implement. Meetings with state agencies (Department of Mental Retardation and MassHealth) and other stakeholders are next steps for implementing this recommendation.

¹⁴ In addition the focus group findings on this matter, this issue has been raised at Health Care Steering Committee meetings by members, such as Dr. Marc Emmerich who personally interacts with many community support staff during medical appointments.

Respondents in the focus groups felt they needed more information to be better advocates for their health care. Training, ideally, would include role modeling by peers. New efforts in health care advocacy focus on simple educational fact sheets (The Partnership for Health Care Excellence, n.d.). This is something that organizations, such as The Arc of Massachusetts, can leverage or utilize.

VI. Conduct Additional Research

- Investigate the utilization and access to health care specialists, including the gaps in specialist care.
- Review the availability of sign interpreters and language translators.
- Incorporate disability, including the impact of intellectual and/or developmental disabilities (ID/DD), into health disparity research.
- Compare the cost effectiveness of certain strategies to address the quality of care and care coordination issues.
- Examine best practices of individuals with ID/DD from diverse communities

Discussion: There are a number of issues that would benefit from further research. The availability of certain health care specialists, such as gynecologists and mental health therapists, needs to be further explored. More research needs to be completed to identify the availability of specific health care professionals because this study was able to confirm a need for dentists and psychiatrists and mental health consultative services for adults with ID/DD.

There continue to be issues with interpretation and translation, including sign and non-English languages. Research focused on cost effective strategies could further the availability of such services.

The inclusion of disability into the health disparities dialogue is critical; without incorporating this group, the population will be omitted from future improvements. However, it is important to assure that research includes exploration of the impact on individuals with ID/DD. Focusing on the impact of physical impairments alone would be a mistake.

Research on cost effectiveness of professionals' roles in care coordination will help identify the best intervention strategies. Such research should explore the best utilization of the primary care physician, nurse practitioner, nurse, and social worker (as formal care coordinator).

Research on best practices of individuals with ID/DD from diverse, multicultural communities should explore how values and cultural practices affect the delivery of communication, health care services and outcomes, and education. Additionally, this study identified a higher proportion of individuals with disabilities from multicultural communities who continue to live with family members, which introduces a question. Is this due to cultural practices or the lack of connections to the service system?

CLOSING REMARKS

We recognize that individuals with disabilities, including those with intellectual/developmental disabilities (ID/DD), are not sufficiently considered when health care systems are constructed or re-evaluated. Individuals with disabilities, particularly those with ID/DD, have faced significant discrimination in our society. The barriers to high-quality health care services reflect, in part, this reality. Addressing the specific barriers alone will not be enough. The Arc and other organizations must work to educate the public at large while facilitating grassroots advocacy. Such work can only be completed with the generous support of funders and donors. Additionally, the Commonwealth of Massachusetts, through its responsible state agencies, must use its significant power to address these inequities. Such work can be integrated into the Governor's Community First Olmstead Plan (Massachusetts Executive Office of Health and Human Services, 2008); however, Community First is not enough. There is no second place to life in the community. Our supports, health, education, transportation, among others, must catch up to this reality if proper respect is paid to all of our fellow citizens.

REFERENCES

- American Academy of Family Physicians, Strong Medicine for America. (2008). *Patient centered medical home: Highlights*. Retrieved October 27, 2008, from http://www.aafp.org/online/etc/medialib/aafp_org/documents/about/pcmhsum.Par.0001.File.tmp/PCMHsummary.pdf
- American Association on Intellectual and Developmental Disabilities. (n.d.). *Definition of intellectual disability*. Retrieved November 20, 2008, from http://www.aamr.org/content_100.cfm?navID=21
- American Network of Community Options and Resources. (2008, August 25). *You need to know me. I am a direct support professional. ANCOR – national advocacy campaign*. Retrieved October 30, 2008, from http://www.ancor.org/issues/shortage/DSP_and_HR_1279_Background.pdf
- Andry, C., Emmerich, M., and Cerreto, M. (2004, June 3). *Here to help: Disability advocacy program*. Boston Medical Center. PowerPoint presented at 2004 Annual Meeting of American Association on Mental Retardation. Retrieved October 21, 2008, from American Association on Intellectual and Developmental Disabilities Web site: http://www.aamr.org/content_498.cfm?navID=142
- Bachman, S. S., Tobias, C., Master, R., Scavron, J., & Tiernery, K. (2008). A managed care model for Latino adults with chronic illness and disability. *Journal of Disability Policy Studies, 18*, 197-204.
- Braddock, D., Emerson, E., Felce, D., Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia [Electronic version]. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 115-121.
- Braden, K. (2002). *Appendix d: Health disparities and mental retardation: Programs and creative strategies to close the gap*, from Closing the Gap: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Retrieved October 21, 2008 from, National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development Web site: <http://www.nichd.nih.gov/publications/pubs/closingthegap/sub18.cfm>
- Brawarsky, P., Brooks, D., Mitra, M., & Chung, M. (2001, November). *A profile of Massachusetts adults with disabilities, 1998 – 2000*. Retrieved August 21, 2007, from Massachusetts Executive Office of Health and Human Services, Department of Public Health, Bureau of Family and Community Health Web site: http://www.mass.gov/Eeohhs2/docs/dph/behavioral_risk/disability_98_00.pdf
- Centers for Disease Control and Prevention. (2004, October). *Developmental disabilities*. Retrieved October 21, 2008, from <http://www.cdc.gov/ncbddd/dd/dd1.htm>
- Centers for Disease Control and Prevention. (2004, December). *Healthy people 2010: Healthy people with disabilities*. Retrieved October 21, 2008, from http://www.cdc.gov/ncbddd/factsheets/DH_hp2010.pdf
- Commonwealth Care Alliance. (2008). *Welcome to Commonwealth Care Alliance*. Retrieved October 27, 2008, from <http://www.commonwealthcare.org>
- Consumers Union. (2008). *Stop hospital infections: End hospital secrecy and save lives*. Retrieved October 24, 2008, from <http://www.stophospitalinfections.org/learn.html>

- Crowley, J., & O'Malley, M. (2006, December). *Profiles of Medicaid's high cost populations*. Retrieved October 29, 2008, from The Henry J. Kaiser Family Foundation Web site: <http://www.kff.org/medicaid/upload/7565.pdf>
- Drainoni, M., Lee-Hood, E., Tobias, C., Bachman, S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access: Consumer perspectives [Electronic version]. *Journal of Disability Policy Studies, 17*(2), 101-115.
- Drum, C. E., Krahn, G., Culley, C., & Hammond, L. (2005). Recognizing and responding to the health disparities of people with disabilities [Electronic version]. *California Journal of Health Promotion, 3*, 29-42.
- Ellwood, M. & Kell, M. (2003, August). *Using MSIS data to analyze Medicaid eligibility and managed care enrollment patterns in 1999*. Retrieved October 29, 2008, from Mathematica Policy Research, Inc. Web site: <http://www.mathematica-mpr.com/publications/PDFs/msisdataanalyze.pdf>
- Fenton, S. J., Hood, H., Holder, M., May, Jr., P. B., & Mouradian, W. E. (2003). The American academy of developmental medicine and dentistry: Eliminating health disparities for individuals with mental retardation and other developmental disabilities. *Journal of Dental Education, 67*, 1337-1344.
- Fisher, K. (2004). Nursing care of special populations: Issues in caring for elderly people with mental retardation. *Nursing Forum, 39*, 28-31.
- Harder + Company Community Research. (2008, September). *A blind spot in the system: Health care for people with developmental disabilities. Findings from stakeholder interviews*. Available from the Family Medicine Education Consortium Web site: <http://www.fmec.net/collaborate/>
- Havercamp, S. M., Scandlin, D., & Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disabilities in North Carolina [Electronic version]. *Public Health Reports, 119*, 418-426.
- Hayden, M. F., Kim, S. H., & DePaepe, P. (2005). Health status, utilization patterns, and outcomes of persons with intellectual disabilities: Review of the literature [Electronic version]. *Mental Retardation, 43*, 175-195.
- Henry J. Kaiser Family Foundation. (2007, January). *Key facts: Race, ethnicity, and medical care*. Retrieved October 29, 2008, from <http://www.kff.org/minorityhealth/upload/6069-02.pdf>
- Horwitz, S., Kerker, B., Owens, P., & Zigler, E. (2000). *The health status and needs of individuals with mental retardation*. Yale University School of Medicine, Department of Epidemiology and Public Health. Retrieved from Special Olympics, Inc. Web site: http://www.specialolympics.org/NR/rdonlyres/e51q5czkqv5vwulp5lx5tmny4mcwhyj5vq6euzrooqcaekeuvmkg75fd6wnj62nhlsprlb7tg4gwqtu4xffauxzsge/healthstatus_needs.pdf
- Iezzoni, L. I., Killeen, M. B., & O'Day, B. L. (2006). Rural residents with disabilities confront substantial barriers to obtaining primary care. *Health Services Research, 41*, 1258-1275.
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities [Electronic version]. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 70-82.
- Lewis, M., Lewis, C., Leake, B., King, B., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities [Electronic version]. *Public Health Reports, 117*, 174-184.

- Massachusetts Consortium for Children with Special Health Care Needs. (2002). *Medical home status for children with special health care needs in Massachusetts: Background brief*. Retrieved November 3, 2008, from <http://www.neserve.org/maconsortium/pdf/Medical%20Home/Medical%20Home%20Brief%20-%20July%202002.pdf>
- Massachusetts Department of Mental Retardation. (n.d.). *Health promotion and coordination initiative*. Retrieved October 27, 2008, from <http://www.mass.gov/?pageID=eohhs2subtopic&L=6&L0=Home&L1=Provider&L2=Guidelines+and+Resources&L3=Guidelines+for+Services+%26+Planning&L4=Mental+Retardation+Support&L5=Health+Promotion+and+Coordination+Initiative&sid=Eeohhs2>
- Massachusetts Executive Office of Health and Human Services. (2008). *The Community First Olmstead Plan*. Retrieved October 22, 2008, from http://www.mass.gov/Eeohhs2/docs/press_release_docs/080912_comm_living_options.pdf
- Norlin, C. (2008, April). *Optimal coding*. Retrieved October 21, 2008, from Utah MedHome Portal Web site: <http://www.medhomeportal.org/about/optimal-coding>
- O'Day, B., Killeen, M. B., Sutton, J., & Iezzoni, L. I. (2005). Primary care experiences of people with psychiatric disabilities: Barriers to care and potential solutions. *Psychiatric Rehabilitation Journal*, 28, 339-345.
- Office of Minority Health and Health Disparities. (2007, October 23). *Disability*. Retrieved July 15, 2008, from <http://www.cdc.gov/omhd/Populations/Disability/Disability.htm>
- Office of the Surgeon General. (2002). *Closing the gap: A national blueprint to improve the health of persons with mental retardation*. A report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Washington, D.C. Retrieved October 10, 2007 from, <http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>
- Office of the Surgeon General. (2005). *The Surgeon General's call to action to improve the health and wellness of persons with disabilities*. Retrieved October 11, 2007 from, <http://www.surgeongeneral.gov/library/disabilities/calltoaction/calltoaction.pdf>
- Ouellette-Kuntz, H. (2005). Understanding health disparities and inequalities faced by individuals with intellectual disabilities [Electronic version]. *Journal of Applied Research in Intellectual Disabilities*, 18, 113-121.
- Patient Centered Primary Care Collaborative. (2007, February). *Joint principles of the patient centered medical home*. Retrieved October 21, 2008, from <http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home>
- Patient Centered Primary Care Collaborative. (2008, October 17). *October 17th 2008 – Annual summit agenda*. Retrieved October 21, 2008, from <http://www.pcpcc.net/content/october-17th-2008-annual-summit-agenda>
- Reichard, A., Sacco, T. M., & Turnbull, III, H. R. (2004). Access to health care for individuals with developmental disabilities from minority backgrounds. *American Association on Mental Retardation*, 42, 459-470.
- Special Olympics, Inc. (2005). *Changing attitudes changing the world: The health and health care of people with intellectual disabilities*. Retrieved September 5, 2008, from http://www.specialolympics.org/NR/rdonlyres/e75okatixbknehtnruotheossutueniq7hsd6ev6bg3astpgwfmabbzfwy5ph2tbjz3gnjuzum6hhbjgljh6nl36d/CACW_Health.pdf

- Steinmetz, E. (2006). *Americans with disabilities: 2002 household economic studies*. U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau. Retrieved November 4, 2008, from U.S. Census Bureau Web site: <http://www.census.gov/prod/2006pubs/p70-107.pdf>
- The Arc of Greater Boston. (2008, March 16). *Operation house call*. Retrieved October 21, 2008, from <http://www.arcgb.org/housecall.htm>
- The Arc of Massachusetts. (2008, September 16). *The Arc of Massachusetts platform: 2007-2008 legislative session*. Retrieved October 27, 2008, from <http://www.arcmass.org/StateHousePolicy/BillsTheArcsLegislativePlatform/tabid/135/Default.aspx>
- The National Center of Medical Home Initiatives for Children with Special Needs. (2007). *Tools for coordinating care: Toolkits and guides*. Retrieved October 29, 2008, from <http://www.medicalhomeinfo.org/tools/Toolkits.html>
- The National Center of Medical Home Initiatives for Children with Special Needs. (2008). *What is a medical home?* Retrieved December 5, 2008, from <http://www.medicalhomeinfo.org/Medical%20Home%20Talking%20Points%20Final%20Version-%20Word.doc>
- The Partnership for Health Care Excellence. (n.d.). *Factsheets*. Retrieved October 27, 2008, from <http://www.partnershipforhealthcare.org/resources/factsheets.asp>
- The Partnership for Health Care Excellence. (2007). *Welcome to The Partnership for Healthcare Excellence*. Retrieved October 21, 2008, from <http://www.partnershipforhealthcare.org>
- The President's Committee for People with Intellectual Disabilities. (2007). *About the committee*. Retrieved October 17, 2008, from http://www.acf.hhs.gov/programs/pcpid/pcpid_about.html
- U.S. Census Bureau. (2006). *Americans with disabilities act: Facts for features and special additions*. Retrieved October 22, 2008, from http://www.census.gov/Press-Release/www/releases/archives/facts_for_features_special_editions/006841.html
- U.S. Department of Health and Human Services, Government Printing Office. (2000). *Healthy people 2010: Understanding and improving health*. Retrieved October 23, 2007, from http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/16/5b/77.pdf

APPENDIX A: Self-Advocate Focus Group Participants

Age:		
Mean	48 years	
Range	28 - 74 years	
Gender:*		
	N	%
Male	5	29.4
Female	12	70.6
Living Situation:*		
Alone	10	58.8
Group Home/Apartment	4	23.5
With parent	1	5.9
Other	2	11.8
Ethnicity Race:*		
American Indian	1	6.25
African American	1	6.25
Latino/a	1	6.25
White	11	68.75
Other	2	12.5
Marital Status:*		
Single	11	68.8
Divorced	1	6.25
Married	4	25
Current Employment Status:*		
Employed	10	62.5
Unemployed	6	37.5
Insurance Coverage:*		
MassHealth only	9	52.9
MassHealth and Medicare	4	23.5
MassHealth and Private	3	17.6
Private only	1	5.88
Income: *		
Employment and SSI/SSDI/SSS	7	43.8
Employment only	2	12.5
SSI/SSDI	4	25
Family only	1	6.25
SSI/Family	1	6.25
Employment/TANF	1	6.25

*Note. No answer from some respondents

APPENDIX B: Parent/Guardian Focus Group Participants

Age:		
Mean	57 years	
Range	36 - 76 years	
Gender:	N	%
Male	9	22
Female	32	78
Ethnicity/Race:*		
Asian	2	5.1
African American	9	23.1
Latino/a	11	28.2
White	13	33.3
Haitian	4	10.3
Primary Language Spoken:*		
English	19	47.5
Spanish	11	27.5
Haitian Creole	10	25
Marital Status:*		
Single (Separated/Divorced)	21	52.5
Married	19	47.5
Legal Guardian of Adult Son/Daughter:*		
No	4	10.3
Yes	35	89.7
Adult Son's/Daughter's Living Situation:*		
With Parents	27	71.1
Group Home/Apartment	11	28.9
Adult Son's/Daughter's Insurance:*		
MassHealth only	25	65.8
MassHealth and Private	10	26.3
MassHealth and Medicare	3	7.89
Adult Son/Daughter's Current Employment Status:*		
Employed	9	23.7
Unemployed	29	76.3
Adult Son/Daughter's Diagnosis:	Frequencies	
Mental Retardation	17	
Autism	7	
Cerebral Palsy	7	
Epilepsy/Seizures	6	

*Note. No answer from some respondents

APPENDIX C: Community Support Professional Focus Group Participants

	N	%
Agency Type:*		
Residential	29	52.7
Day Services	11	20
Other	15	27.3
Primary Insurance of Agency Clients:		
MassHealth	27	93.1
Medicare	1	3.4
Private	1	3.4
Highest Degree:*		
High School	7	12.7
Associates	18	32.7
College	20	36.4
Graduate	9	16.4
Post-Graduate	1	1.8
Professional Discipline:*		
Nursing	30	61.2
Human Services	9	18.4
Social Work	3	6.1
Education	3	6.1
Business	2	4.1
Public Health	1	2
Ministry	1	2
Years in ID/DD Profession:*		
1 - 5	13	25.5
6 - 10	7	13.7
11 - 15	11	21.6
16 - 20	6	11.8
21 - 25	5	9.8
26 and over	9	17.6

*Note. No answer from some respondents

APPENDIX D: Self-Advocate Focus Group Guide

1. When you go to the doctor or to other medical appointments, how do they treat you?
 - a. How do they treat you and/or talk to you?
 - b. How do they understand your needs and what you want?
2. If you have ever had to go to the hospital, what happens when you talk or communicate with medical staff in the hospital?
 - a. How do they treat you?
 - b. What do they say about your health (medical) needs?
 - c. How do they understand your needs and what you want?
3. How do you feel about the care you get from the primary person who takes care of your medical needs? (For example, the doctor or nurse)
 - a. How do you get the health (medical) care you need?
 - b. How do you feel about getting the health (medical) care you need?
 - c. What about the staff in the medical office (for example, the secretary)?
 - d. What does the person who takes care of your medical needs do to help you from getting sick?
4. What have your experiences been in getting extra medical help (either referrals from your primary doctor or when you go to a specialist)?
5. How did you find or locate the primary person who takes care of your health (medical) needs?
 - a. When you were trying to find them, what worked well?
 - b. What didn't work so well?
 - c. What did you have to do to become their patient?
6. What have been your experiences with your insurance and getting any type of medical care?
 - a. What about medical specialists (for example, dentist, eye doctor)?
 - b. If you have needed to see someone other than the primary person who takes care of your medical needs (also known as your primary doctor), what was that experience like?
 - i. How was the communication between you and them?
7. What should medical staff know about individuals with intellectual and/or developmental disabilities (ID/DD)?
8. If you could create a better way for people who have ID/DD to get the medical help they need, what would it look like?
 - a. What would make getting health care easier?
 - b. Any suggestions about getting health care?

APPENDIX E: Parent/Guardian Focus Group Guide

1. When you accompany your adult son/daughter to a medical appointment, what happens when they communicate with the person who takes care of their medical needs?
 - a. How does the medical staff treat your son/daughter?
 - b. What does the medical staff say about their disability?
2. If you have ever had to accompany your adult son/daughter to the hospital for medical care, what happens when they communicate with medical staff?
 - a. How does medical staff treat your son/daughter?
 - b. What does the medical staff say about their disability?
3. How do you feel about the care your adult son/daughter receives from the person who takes care of their medical needs?
 - a. How do you feel about getting the care your adult son/daughter needs?
 - b. What have been your experiences with getting your adult son/daughter extra (specialist) medical help?
 - c. What does the primary person taking care of your adult son/daughter's medical needs do to help them from getting sick?
4. How did you find the person who takes care of your adult son/daughter's medical needs?
 - a. When you were trying to find them, what worked well?
 - b. What didn't work so well?
 - c. What did you have to do to get your son/daughter in to that medical practice?
5. What have been your experiences with your adult son/daughter's insurance and getting any type of medical care?
 - a. If your adult son/daughter has needed to see someone other than the person who takes care of their medical needs, what was that experience like?
 - b. How was the communication between them and your son/daughter?
6. What should medical staff know about individuals with intellectual and/or developmental disabilities (ID/DD)?
 - a. If you could create a better way for people who have ID/DD to get the medical help they need, what would it look like?
 - b. What would make getting health care easier?
 - c. Do you have any suggestions about getting health care?

APPENDIX F: Community Support Professional Focus Group Guide

1. What do primary care physicians (PCPs) know about special health care needs of individuals with intellectual and/or developmental disabilities (ID/DD)?
 - a. What have been your experiences with primary care givers' having specific knowledge about a consumer's health (medical) needs that are related to their ID/DD?
2. How and are adults with ID/DD getting the medical treatment they need?
 - a. If receiving treatment needed, give examples of treatment given.
 - b. If not receiving treatment, what is missing?
 - c. What have been your experiences with consumers not receiving treatment for treatable medical conditions?
3. What do PCPs do to address appropriate or needed medical treatment of individuals with ID/DD?
 - a. What health promotion activities are discussed?
 - b. What can physicians do to promote health with consumers?
4. What do PCPs know about behavioral health needs of individuals with ID/DD?
 - a. How are they recognized?
 - b. How are they addressed?
 - c. What typically happens when consumers have disruptive behaviors in medical appointments?
 - d. What do you think can be done to assist clients who have disruptive behaviors in medical appointments?
5. What do physicians expect of consumers during their medical appointments?
6. What is your role at medical appointments?
7. What types of opportunities have you had to learn about medical needs of individuals with ID/DD?
 - a. What types of opportunities would be most helpful to you?
8. What have been your experiences with insurance or managed care when it comes to the medical needs of individuals with ID/DD?
9. What should medical staff know about individuals with ID/DD?
 - a. What can be done to increase health care access?
10. If you could create a better way for people who have ID/DD to get the medical help they need, what would it look like?
 - a. What would make getting health care easier?
11. What outstanding experiences have you had with medical providers?
12. What would you like to share about health care access and quality for individuals with ID/DD?

APPENDIX G: Health Care Professional Interview Guide

1. What is the estimated number of adult patients with intellectual and developmental disabilities (ID/DD), those over 18, within your practice?
2. Adult patients with ID/DD are what percentage of your total practice?
3. What is the primary source of insurance coverage for adult ID/DD patients?
4. What is your understanding of the barriers or challenges patients with ID/DD face when accessing quality health (medical) care?
5. What has been your experience in sharing information and communicating with adult patients with ID/DD and their families? Please provide examples of what has worked well and what has been challenging.
6. What has been your experience in sharing information and communicating with adult patients with ID/DD and residential/group home staff? Please provide examples of what has worked well and what has been challenging.
7. What has been your experience in care coordination with adult patients with ID/DD and their families? Please provide examples of what has worked well and what has been challenging.
8. What has been your experience in care coordination with adult patients with ID/DD and residential/group home staff? Please provide examples of what has worked well and what has been challenging.
9. Can you talk about what limits your ability to treat adult patients with ID/DD? If applicable, please include information about (a) reimbursement rates for private/public insurance providers, (b) medical practice facilities, (c) medical staff, (d) family/guardians, and/ or (e) group/residential staff.
10. If you could design a solution for accessing quality health care for adult patients with ID/DD, what is needed?

APPENDIX H: State Legislator Interview Guide

1. Please share any impressions or specific knowledge that you may have regarding the health care needs of adult patients with intellectual/developmental disabilities (ID/DD).
2. What is your understanding of barriers or challenges faced by adult patients with ID/DD when accessing health care in community settings? In hospital settings?
3. Do you have any opinions of how present insurance reimbursement policies further or impede delivery of quality health care to individuals with ID/DD?
4. What is the range of health care issues that you work on in your role as a policymaker *OR* what is the range of health care issues and some examples of health care policy issues that your legislative committee is involved in?
5. If you could design a solution for accessing health care for adult patients with ID/DD, what is needed? (Probes: legislation, funding, insurance, family support, preventative care, etc).
6. If specific barriers to quality health care for individuals with ID/DD are identified, what information would you or your committee require to take remedial action?

Only ask the following question if the respondent is knowledgeable of the ID/DD population:

7. In your view, what does good access to quality health care look like for individuals with ID/DD?

APPENDIX I: Insurance Provider Interview Guide

1. Can you talk about the estimated number of patients with intellectual and/or developmental disabilities (ID/DD) you serve and how this data is collected?
 - a. And out of this estimated number, how many also receive Medicaid?
 - b. How many receive Medicare?
 - c. And how many receive Medicaid and Medicare?
2. Can you talk about your specific knowledge regarding the health (medical) care needs of adult patients with ID/DD?
 - a. Regarding this knowledge, who has been the primary source of this information?
3. What is your understanding of the barriers or challenges faced by adult patients with ID/DD when accessing quality health care?
4. Can you talk about any special allowances, regarding insurance protocols/procedures, for medical providers who serve patients with ID/DD?
5. Thinking about your experiences and interactions with medical providers, what insurance concern/issue is reported the most regarding their service to patients with ID/DD?
6. Can you talk about how reimbursement rates are established for medical providers who serve patients with ID/DD?
7. Are reimbursement rates impacted by patients having multiple insurance providers (e.g., Medicaid, Medicare, private)?
8. From your experience, what types of partnerships have providers established in order to serve patients with ID/DD?
 - a. In your view, what partnerships can be formed between practitioners and insurance providers for better care of adult patients?
9. Can you talk about what the insurance industry is most concerned about when it comes to the health (medical) care of adult patients with ID/DD?
10. In your view, what does good access to health care look like for patients with ID/DD?

APPENDIX J: Self-Advocate On-line Survey

1. When you go to the doctor's or nurse's office, how does the nurse or doctor talk to you?
2. When you go to the doctor's or nurse's office, how does the receptionist (secretary) talk to you?
3. When you go to the hospital, how do the people in the hospital talk to you?
4. When you go to the dentist's office, how does the dentist talk to you?
5. When you go to the dentist's office, how does the receptionist (secretary) treat you?
6. What do you think about your medical insurance?
7. What should doctors and nurses know about people with intellectual and/or developmental disabilities?
8. If you could create a better way for individuals with intellectual and/or developmental disabilities to receive the medical care they need, what would that better way look like?

APPENDIX K: Parent/Guardian On-line Survey

1. Please describe the communication between your adult son/daughter/family member with intellectual and/or developmental disabilities (ID/DD) and the medical staff at his/her primary care physician's office.
2. Please describe what happens when you accompany your adult son/daughter/family member with ID/DD to the hospital for medical care.
3. Please talk about whether the level of insurance coverage your son/daughter/family member with ID/DD receives is appropriate for his/her medical needs?
4. What are your experiences in getting your adult son/daughter/family member with ID/DD specialty medical care or extra medical care?
5. What should doctors and nurses know about people with ID/DD?
6. If you could create a better way for people with ID/DD to receive the medical care they need, what would that better way look like?

APPENDIX L: Community Support Professional On-line Survey

1. Please describe your experiences with primary care givers having the knowledge concerning health (medical) issues that are directly related to an adult patient's intellectual and/or developmental disability (ID/DD).
2. Please describe how health care professionals communicate with adult patients with ID/DD during medical appointments.
3. Please describe what typically happens when adult patients with ID/DD display disruptive behaviors at medical appointments.
4. Please talk about your role at medical appointments.
5. Please talk about any opportunities you have had to learn about the medical needs of individuals with ID/DD.
6. Please describe your experiences with insurance providers and/or managed care providers when attempting to coordinate medical care for adult patients with ID/DD.
7. If you could create a better way for people with ID/DD to receive the medical care they need, what would that better way look like?



Realizing potential. Achieving goals.

The mission of The Arc of Massachusetts is to enhance the lives of individuals with intellectual and developmental disabilities and their families. We accomplish this through advocacy of supports and services based in the community.



As a united advocacy network with chapters and other organizations, The Arc of Massachusetts' leadership has resulted in the following outcomes:

- 1966: Creation of the community system - advocated for and participated in the "Massachusetts Mental Health and Retardation Planning Project."
- 1974: Massachusetts Special Education Law (Ch. 766), first such law in the nation.
- 1975: Massachusetts Consent Decrees by Judge Joseph Tauro establishes "Community Plan" as a foundation of current community supports and services.
- 1983: Landmark Turning-22 law enacted for special education high school graduates.
- 1999: Rolland Settlement assists 800 individuals with disabilities move from nursing homes.
- 2000: Boulet Settlement assists 2,444 individuals on Department of Mental Retardation's Waiting List.
- 2008: Governor announces "Community First Plan"; outlines closure of four institutions.

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