

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

Executive Summary



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Prepared by



Supported by



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 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

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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 health care settings and hospitals.

The health care needs of this population are often overlooked as health systems become more complex and insulated (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, & Maisels, 2006). The U.S. Surgeon General's report (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 health care than the general population.

## THE ARC OF MASSACHUSETTS



The Arc of Massachusetts is a nonprofit disability organization that advocates on behalf of and represents the interest of 180,000 individuals with ID/DD and their families. We accomplish this through advocacy of supports and services based in the community.

The Health Care Project's Research Team members have worked diligently on this study and publication of the report<sup>1</sup>: Amanda D. Nichols, M.S.W. (Project Director); Rolanda L. Ward, M.S.W., M.Div. (Research Assistant); and Ruth I. Freedman, M.S.W., PhD (Senior Research Consultant).

The Health Care Project's Steering Committee plays a valuable role and consists of family members and health care professionals: 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

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<sup>1</sup> *Note from Project Director:* Additional contributors to this report include The Arc of Massachusetts' Executive Director, Leo V. Sarkissian, M.S.W. and Community Relations Manager, Judy Zacek, PhD.

Inc.); Mary Ellen Mayo, RN, MS (Immediate Past President of The Arc of Massachusetts); Janet Sweeney Rico, PhDc, MBA, NP-BC (Simmons Graduate School for Health Sciences); Leo V. Sarkissian (Executive Director of The Arc of Massachusetts); and Donald Stewart, MBA (The Concurrency Group).

## PRIMARY FUNDER OF THE PROJECT

The Boston Foundation 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](http://www.tbf.org) or call 617-338-1700.

## METHODS

Three data collection strategies were utilized in 2007 and 2008 to obtain health care experiences of a broad and diverse group of respondents in Boston, the greater metropolitan area, and western Massachusetts. See Table 1. This study was approved by the Massachusetts’ Department of Mental Retardation’s Research Review Committee.

Table 1: Data Collection

Participant	Focus Groups (N)	Informant Interviews (N)	On-line Surveys
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	
Health 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

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Across focus groups and health care professional key informant interviews, respondents identified seven key, salient themes<sup>2</sup>. The state legislator and health insurance provider responses were not included in the following themes because their knowledge and experiences of the ID/DD population's health care needs and barriers were limited. See Additional Key Informant Findings.

### *I. Knowledge*

Health care professionals lack sufficient knowledge about how to care for patients with ID/DD. 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

### *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. Four main categories were identified by the respondents:

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

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<sup>2</sup> The seven themes are based on self-advocate, parent/guardian, and community support and health care professional participant responses, unless otherwise noted.

professionals who develop a good rapport and utilize strategic actions to facilitate communication

### **III. 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

### **IV. Access**

The ability to access timely preventative and as-needed medical care services was vital and very important to all groups. Respondents identified four main categories:

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 a health care professional

## ***V. Insurance***

Insurance coverage alone does not guarantee access to qualified health care professionals and necessary medical services. Three key categories were shared by the respondents:

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

## ***VI. Care Coordination***

Care coordination is not a standard practice for patients with ID/DD. Three main categories were identified by the respondents:

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

## ***VII. Respondents' Recommendations***

Many recommendations were suggested 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**

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As previously mentioned, the state legislator and health insurance provider interviews were summarized due to their limited experiences and knowledge of the ID/DD population's health care barriers and needs.

### **Summary of State Legislator Interviews**

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.

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 health insurance providers had limited knowledge of the 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 health care needs of the ID/DD population.

Although respondents had limited knowledge about the direct health care needs of patients with ID/DD, most stated 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 the full report: health care professionals think reimbursement rates are too low.

## **PROJECT TEAM'S RECOMMENDATIONS**

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

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

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The full report will be available through and posted on The Arc of Massachusetts' web site: [www.arcmass.org](http://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*.

The full report includes organizations and groups who hosted focus groups and those involved in outreach, respondents' quotes and demographics, Project Team's discussion of proposed recommendations, focus group and interview guides, and on-line survey questionnaires.



## The Arc of Massachusetts

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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.