



For people with intellectual  
and developmental disabilities

The Arc of Massachusetts  
217 South Street  
Waltham, MA 02453-2710

T: 781.891.6270  
F: 781-891.6271  
arcmass@arcmass.org  
www.arcmass.org

*Achieve with us.*

Deborah Norton  
President

Leo V. Sarkissian  
Executive Director

## Resolving the Workforce Crisis: Appendix A

### Addressing Lack of Specialists & Clinical Teams in the Workforce

#### *What do we mean by “Addressing lack of specialists/clinical teams”?*

**Executive Summary** - Despite the efforts of many people, the Massachusetts system of community services and supports is not adequately meeting the health needs of two groups:

1. Some individuals with intellectual and developmental disabilities including autism<sup>1</sup> (I/DD) who present differently than typical patients and/or present with low incidence health challenges; and,
2. Aging individuals with I/DD with complex medical and behavioral health needs.

The unmet needs of these two groups leads to diminished quality of life for both groups and also can significantly impact other family members. Well-trained health professionals and clinicians able to provide consultation to address the health needs of both groups are needed. The Arc of Massachusetts proposes that a network of regional clinical consultation teams be funded and developed to address these urgent needs. These teams would provide consultation services to:

- clinicians and health care professionals utilized by our constituents;

---

<sup>1</sup> Throughout this document the abbreviation I/DD will be used when referring to individuals with intellectual and developmental disabilities including autism.

---

The Arc in Massachusetts Includes the Following Local Chapters:

Berkshire County • Bristol County • Brockton Area • Cape Cod • Center of Hope Foundation  
Charles River Center • East Middlesex • Greater Haverhill-Newburyport • Greater Lawrence • LifeLinks • Greater Plymouth • Minute Man  
AHS Northeast • The Arc of Opportunity (North Central) • South Norfolk County • South Shore • The United Arc

- community day and residential providers supporting these individuals; and,
- caregiving families.

Below, we offer brief examples of the challenges and, in the second section, recommend a general strategy for addressing them.

## **The Challenges**

### **For Individuals with I/DD**

When individuals with I/DD have unmet or inadequately addressed health needs, including mental and behavioral health needs, adverse personal outcomes can result for the individual such as diminished quality of life, limited community involvement, and in some cases, reduction in life expectancy.

Caregiving family members can suffer similar outcomes.

Following is a sampling of frequent issues:

- a) Physical health challenges – Some individuals with I/DD present with significant physical health challenges, which can vary widely. Examples include: difficult to diagnose GI conditions, a seizure disorder that does not respond to available medication treatment, conditions that result in the individual having diminished sensation or ability to move (which can lead to risk for skin breakdown), poor dental health, morbid obesity, diabetes, and medical and clinical issues related to aging and the possibility of early dementia or Alzheimer’s disease. Additionally, a small percentage of individuals with I/DD are born with very low incidence genetic conditions, e.g., Rett Syndrome, or metabolic issues such as Factor VII Disorder (a blood clotting disorder) that may require on-going access to medical care.
- b) Mental/behavioral health challenges – Individuals with I/DD may also present with mental or behavioral health challenges, some of which are untreated or undertreated. The nature of these challenges can vary widely, from easily recognized cases of bipolar disorder or psychosis, to

cases that are very difficult to recognize because the interaction of the mental health disorder and the person's I/DD presents a symptom array that can frequently confuse both those reporting the issues and the attending professional responsible for diagnosis and treatment.

Detection can also be difficult since some individuals with I/DD may have had some challenging life experiences, so reports of symptoms such as avoidance of others, overeating, or verbal or physical aggression associated with chronic irritability may be dismissed as "par for the course." In other cases, the individual's behavioral health challenges may be tolerable, and it may be decided that treatment should not be pursued. Other times, the mental or behavioral health challenges are such that they severely limit the person's community involvement and thus, may result in diminished health and/or danger to the individual or others.

Some mental/behavioral health challenges can also be difficult to assess due to an interplay of factors. For example, an individual who is not able to communicate very well can present with "*moaning, yelling and increased refusal of food*" as the primary concerns. It may be clear there is a behavioral health challenge, but it may be unclear if the symptoms are related to unmet or under addressed physical health needs. For example, the underlying issues may include:

- unrecognized dental or gastrointestinal issues resulting in pain;
- irritability as part of unrecognized depression resulting in social withdrawal and some instances of verbal and even physical aggression.
- a history of trauma that is unknown, or underappreciated, and a resulting trauma connected response (withdrawal, fearfulness) that has been triggered by an event unwitnessed by the family or staff presenting the individual to the health care professional.

Other mental/behavioral health challenges may be related to non-health factors, such as limitations in the support options available. Consider an individual presenting with disruptive behavior or one who reliably does not ‘follow the rules’ in a home or day program setting. The underlying issues may be related to:

- A poor match between the individual’s support needs and the environment in which the person receives services. For example, when a person uses sign language, but the staff supporting him have limited ability in that domain, or when a woman needs assistive technology support to communicate basic wishes, but that service is not available to her.
- Cases in which the individual’s behavioral health challenge is related to a need for skills, as when an individual lacks a foundational skill such as being able to wait, or seek assistance, or safely engage in independent leisure activities; and,
- Cases in which the individual needs compensatory supports as when an individual with pica needs environments in which he lives and engages in day activities to be free of small items that he might ingest.

### **For Family Members and Others Providing In-Home Support**

Family members supporting individuals living at home are the largest group of service providers for individuals with I/DD and eligible for support from the Massachusetts DDS.<sup>2</sup> Family members often provide individuals with critical in-home supports; while this certainly helps to conserve valuable resources that otherwise might need to be purchased by the state, it also presents a significant array of challenges.

---

<sup>2</sup> More than half (53%) of people with IDD receiving a Medicaid-funded service live with their family (Larson, et al, 2018).

As noted above, there are several unmet or under-addressed health needs, including mental and behavioral health needs. According to the FINDS Report, more than half of all *FINDS* Caregivers reported dealing with dangerous or difficult behaviors of the person they support (64%).<sup>3</sup> Based on reports, this can cause increased stress for family members and others providing support and, in some cases, the stress will be enough to negatively affect the health of the family members and other support providers.

Even when the needs of the individual getting in-home support are fully met and the individual is by all accounts thriving, family members and others providing support may need additional help to pursue available resources or to understand how to maximize available supports for the benefit of the individual, especially if they don't have enough information or are fatigued or discouraged. Nine in ten *FINDS* Caregivers reported that they were stressed. Nearly half reported being very or extremely stressed. The number of caregivers reporting that they were very or extremely stressed has increased since the *FINDS* 2010 survey. Caregivers also report difficulties addressing their own health issues (somewhat of a problem 44%; major problem 21%) and finding time to meet their personal needs.<sup>4</sup> In some instances, support groups and/or therapy is available to family members. However, in consideration of the level and frequency of stress that is reported, additional or new types of supports would be a good investment.

In addition, in some cases, family members and others providing supports, sometimes find it difficult to secure professional supports for the individual being supported and this may result in needs not being addressed or overuse of emergency medical supports. Despite good faith efforts by all involved, emergency medical supports are frequently a poor match for the issues being presented by the

---

<sup>3</sup> A. E. Hewitt et al., Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, *FINDS* Community Report 2017, Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. <https://www.thearc.org/FINDS>.

individual with I/DD, nor do they provide continuity of service or long-term solutions. The utilization of emergency care also increases the costs of care.

### **Strategies to Improve Lives and Address the Challenges Identified Above**

The purpose of specialists/clinical teams is to offer consultative support to families, provider agency staff or clinicians (state or private), as well as generic health care professional supporting individuals and families. These experienced clinical practitioners who are knowledgeable about I/DD assist families or individuals to obtain competent care through assisting ongoing health care practitioners and provider agency staff with especially challenging cases; and be utilized, short-term by providers in urgent situations to address a condition or prevent unnecessary emergency room visits or hospitalizations.

Clinical teams will solve three critical issues in the system of services:

- (1) Address complex medical or behavioral situations or those facing access barriers;*
- (2) Appropriate consultation to families to reduce caregiver fatigue and provide improved access to care; and*
- (3) Address the training of staff at every level to assist individuals with I/DD and their families.*

In general, specialists/clinical teams who consult with and offer support to the individuals, their families and support teams, are not readily available. It is imperative to increase the community system's capacity to develop, manage, fund, and otherwise support a network of consulting specialists and clinical teams. These specialists/clinical team services would complement those available and would fill gaps that currently exist.

---

<sup>4</sup> *Id.* A.E. Hewitt et. al. FINDS Community Report 2017 at p. 9.

Why are Expertise and Systems Needed? - The specific supports needed to help improve the quality of life of any individual will vary. It is critical that all professionals working with individuals with I/DD be knowledgeable about their conditions or be open to acquiring the necessary information and be amenable to collegial input. It is recommended that increased Specialist / Clinical Team consultative supports be developed to address the identified problem(s) and educational needs of community providers over time, it is likely that more of these supports could even be offered via a Telehealth format as a way of increasing efficiency.

These teams should have available:

- a. Medical Doctors<sup>5</sup>, Physician's Assistants, and Nurse Practitioners including general practitioners and those with, for example, expertise in psychiatry, neurology, and endocrinology;
- b. Registered Nurses and Licensed Practical Nurses working under a RN's supervision;
- c. Licensed Independent Clinical Social Workers (LICSW) and Social Workers with lesser licenses working under the supervision of a LICSW;
- d. Board Certified Behavior Analysts (i.e., "BCBAs") and/or those with the Massachusetts License in Applied Behavior Analysis (LABA);
- e. Allied Health Professionals, specifically –
  - i. Communication Specialists<sup>6</sup>,
  - ii. Occupational Therapists,
  - iii. Physical Therapists,
  - iv. Dental Hygienists, and
  - v. Dieticians;

---

<sup>5</sup> To include MD, DO.

<sup>6</sup> That is, a properly licensed Speech Therapists expert in working with individuals needing alternative communication systems (vs. more traditional 'speech therapy').

- f. Assistive Technology professionals, i.e. a professional with recognized expertise in identifying and adapting technology for people with I/DD; and,
- g. Psychologists, Licensed Mental Health Clinicians and other licensed clinicians as needed.

Additionally more collaborative work has to be done with institutions of higher education to establish and maintain curricula related to the needs of the full range of individuals with I/DD; in addition, institutions should explore offering an increased number of internships or other experiential opportunities like Physician's House Call and Operation House Call that would give professionals the opportunity to "sample" working with those individuals with I/DD, their families and staff.

Included below are three specialists/clinical teams services that may be worthwhile to study or replicate:

- 1. Early Intervention (EI) services. EI is available to the young (birth to age 3). The EI teams provide valuable guidance and support.

DDS's Northeast Region has two services that are relevant to some of the needs identified above.

Here is a brief description of each of those two DDS services:

- 2. The REACH Clinic.<sup>7</sup> Operated through DDS, REACH provides a variety of relevant services to eligible adults and children living in DDS's Northeast Region. REACH is accessed via DDS through the Area Offices and referrals typically go through the Area Office nurse or Clinical Director (i.e., it is a closed referral system).

Professional disciplines represented on the REACH Clinic Team:

- a. Occupational Therapy (including Sensory and Home Safety)
- b. Physical Therapy (can also assist with equipment)
- c. Recreation
- d. Assistive Tech

---

<sup>7</sup> The REACH Clinic provides evaluations (and advice) but does not provide direct service.

- e. Speech
- 3. The DDS Northeast Region “Clinical Assessment Team”<sup>8</sup> The DDS Team is comprised of a Psychiatrist, Neurologist, Pharmacist, Social Work and Nurse Practitioner. This team can do medication reviews and make recommendations. The Team primarily supports those adult individuals supported by DDS who are “at risk”.

**A Product of the Steering Committee on Policy and Advocacy of The Arc of Massachusetts by Chris Fox, Ph.D. and contributions from other members.**

---

<sup>8</sup> As with the REACH service, the individual must be eligible for DDS services in the Northeast.