



*For people with intellectual  
and developmental disabilities*

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*Achieve with us.*

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**The Arc of Massachusetts  
Testimony for the Commonwealth of Massachusetts Olmstead Plan  
June 30, 2017**

We appreciate the opportunity to submit this written testimony to amplify our oral remarks on June 26, 2017. The Arc of Massachusetts, a nonprofit organization, was established in 1954. Our mission is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. We fulfill this through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society. We represent 200,000 people in our state and their families. Our work is leveraged by 18 affiliates, 40 human service sponsors and other organizations.

The Arc of Massachusetts supports the Commonwealth of Massachusetts' efforts to set new goals through a new Community First Olmstead Plan. In 2008, The Arc provided testimony and evidence on critical next steps for realizing the Plan's 6 goals. It was clear that achievement of the plan necessitated deliberate development of long-term care capacity, particularly regarding greater accessibility to public resources such as Medicaid-funded services, as well as reduction of barriers to fully integrated communities. See Section II of this testimony, 2017 Review of the 2008 Olmstead Plan, for our updated assessments.

In Section 1 below we respond to the 5 questions on Olmstead progress posed by the Commonwealth. Our testimony focuses on those with intellectual and developmental disabilities (I/DD) within the service system context of:

- Where the Commonwealth stands in relation to helping persons with disabilities to best integrate their lives in their communities.
- How public supports/services -- whether provided through MassHealth or the Department of Developmental Services (DDS) -- such as PCA, AFC, community residences/apartments, day habilitation, community based day supports, employment, Autism accounts, and other core services such as family supports -- advance Olmstead's community integration mandate.

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The Arc in Massachusetts includes the following Local Chapters:

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

## Section 1. Response to Olmstead Questions

### **Question 1. How do the current housing and services systems best help individuals with disabilities to integrate into and live successfully in the communities of their choice?**

Statistics provided by MassHealth and the Department of Developmental Services (DDS) show that current systems support tens of thousands of people. Other agencies such as Mass. Commission for the Blind and the Department of Mental Health also provide housing assistance based on need. Using 2015 MassHealth figures, the PCA (personal care attendant) program assisted nearly 30,000 people, and the AFC (Adult foster or family care) program assisted nearly 10,000 constituents. Both programs allow a fair amount of flexibility for people to live as they want.

#### *PCA Program*

The PCA program offers a greater level of flexibility as the AFC program requires a shared living home environment. However, PCA supports *may* not have enough structure through the Personal Care Management (PCM) Services or surrogates for some individuals with I/DD to assist with care coordination when desired or needed.

Pay rates for direct care workers including PCA staff, tend to be inadequate to attract and maintain experienced workers. An inadequate and inexperienced work force is a hindrance to full Olmstead compliance. However, the recent decision to pay PCAs overtime has had two negative impacts. It sets up a slippery slope for the independent use of PCAs, and has caused many attendants to find additional jobs to supplement their PCA work since the Commonwealth cannot afford to pay for unlimited PCA overtime hours. We return to the issue of workforce at other points in this testimony.

#### *AFC Program*

As noted the AFC program can allow people to continue to live in their own communities with biological family connections or non-related housemates. The decision to reimburse family members (made during the Romney Administration), was an effective strategy to help elders and persons with disabilities to reside in their existing community if desired.

#### *Home Health Care*

Home health and related services are an essential service to maintain an individual with medical needs in the community. 2015 reports show that Home Health services reached 33,000 constituents. Another barrier to delivering home-based health care is the rate for block or continuous nursing. These rates have been flat for several years and contribute to its declining nursing workforce. These rates do not have to meet hospital pay, but do need to be within some approximation of competitors' rates.

#### *DDS Residential services*

Residential services at DDS provide a safety net for many people with I/DD who need a combination of supports to live in the community. If a person needs 24/7 support (round the clock, daily assistance for activities of daily living and instrumental ADL), these supports often are the only resort to avoid

institutionalization. Historically, residential group homes were the main approach the Commonwealth used in the deinstitutionalization of state facilities. The Arc strongly supported deinstitutionalization efforts and advocated for a system of flexible supports which include what are now “traditional” staffed homes and apartments. In 2015, DDS served approximately 11,000 people through a range of residential supports. (Sources: <https://mn.gov/mnddc/parallels2/pdf/00s/00/00-DPD-NCS.pdf>; <http://www.kff.org/medicaid/issue-brief/olmsteads-role-in-community-integration-for-people-with-disabilities-under-medicare-15-years-after-the-supreme-courts-olmstead-decision/>; <http://www.nasuad.org/policy/key-issues/ada-and-olmstead>).

Group homes developed in the 1970s and 1980s through legal action resulting in the closure of state facilities (Mass. Consent Decrees, *MARC v. Dukakis*, and *Ricci v. Greenblatt*). In those decades, group homes typically housed 7 or 8 people. Along with group homes, a range of supported living services was simultaneously developed by DDS (initially as part of the Dept. of Mental Health). Supported living offered independent living apartments with drop in staff who could serve as coaches and teachers. In 1989, and later in 2011, Lakin et al produced reports that documented the skill attainment and greater integration progress of those served in community settings than those residing in more costly facilities. (Source: <https://ici.umn.edu/products/prb/212/212.pdf>)

Evolution of DDS residential supports has followed national trends. Under the leadership of Commissioner Howe, DDS prioritized residential placement in shared living arrangements. This approach allows for more individualized attention and hopefully more choice. The assistance is based upon an individual supports plan. Shared living is presumptively a home in a community setting with family or housemate. Group homes now have a maximum of 5 individuals.

Another change is that staffing levels at certain homes have increased to keep pace with the larger number of young people with complex behavioral conditions or medical conditions. Staffing levels provide for nursing with back up, or additional 1:1 if required for behavior management. The disadvantage of staffed homes and apartments is the compromise in location and peer group. People sacrifice choice in location and house mates to receive needed support in the community. The cost of supporting someone independently in residential care who at times requires 1:1 staff or nursing 24/7 would be extraordinary if not delivered in small group settings.

For those forensically involved, temporary stays in settings that are not fully integrated are justified as “step-down” settings. For this population in particular, temporary placements tend to become permanent, especially in times of limited state resources. The Arc also does not support temporary stays for forensically involved individuals with I/DD for this reason.

#### *Revised HCBS Settings Expectations*

The Centers for Medicare and Medicaid Services revised requirements for home and community based settings are helpful to advance community integration. The Arc appreciates the evolution from “staff-focused” operations to constituent-focused, as the revised HCBS setting requirements promote. A constituent-focus allows for more choice by individuals receiving services within their homes, including choice of when to eat, what to do during the day, freedom to receive visitors, etc.

One of the revised settings requirements is that individuals living in provider-owned or controlled HCBS-funded residences must have a lease that is comparable to leases of other general community members. The most recent National Core Indicators data shows that for adults with I/DD receiving services in Massachusetts, providers are the predominant owners of residences (73 percent) compared to residences owned by individuals with I/DD or others such as family members (22 percent). And of those adults living in provider-owned or controlled residences, only 2 percent have a community-comparable lease. (Source: National Core Indicators 2015-16 data, [http://www.nationalcoreindicators.org/upload/state-reports/Massachusetts\\_ACS\\_Report\\_2015.pdf](http://www.nationalcoreindicators.org/upload/state-reports/Massachusetts_ACS_Report_2015.pdf))

Since the HCBS revised settings requirements were published, some are making arguments to expand or maintain campus-like settings, reminiscent of “quality institutions” of the past, presenting these as offering choice. Past research did not support findings of quality of life in institutional settings, and offering segregated campus residential settings as a choice are misinterpretations of the ADA and Olmstead. Segregated settings, even handsomely landscaped campuses, only heighten compromises of choice and control, and physically separate individuals from general community members. These also limit choice in the long-run. Larger settings need to reach a certain census to ensure cost-effectiveness. As with the institutions it would result in pressure upon funders to “fill” openings to maintain stability.

#### *Self-directed services and residential options*

DDS and provider staff are becoming familiar with self-directed options, but large gaps exist in educating Service Coordinators who in turn educate individuals receiving services and family members about this service option. (Source: Draft report to the Real Lives Advisory Commission, June 2017, with findings from Service Coordinator survey on self-direction) Lack of Service Coordinator knowledge and comfort advising families on the self-direction option means a low uptake. In Massachusetts only 3% of adults with I/DD receiving services are utilizing this option. (Source: National Core Indicators 2015-16 data, <http://www.nationalcoreindicators.org/charts/>). Continuing education and training which began in the past 18 months is essential.

Self-directed service options may utilize only DDS funds, but are also useful for enhancing choice in PCA and AFC programs. As the story of Ralph illustrates, these options may also require additional roles on the part of family members or significant friends.

Ralph (not his real name) turned 22 nearly 12 years ago. He is a young adult with autism. His parents knew that he would do best in his own apartment. They were able to obtain an apartment voucher and Ralph used the PCA program. He received employment and day supports from the DDS. His mother obtained some DDS funding to help staff the apartment since there are limitations on the PCA’s role. Over the next 7 years, mom played a key support role overseeing staff schedules and ensuring medical appointments were made, etc. But as Ralph’s mom got older, helping Ralph maintain his apartment was too taxing on her. She was unable to work full-time due to her role, something she needed to do. She advocated for additional funding from DDS and eventually obtained funds that released her to work full-time and let go of a daily role coordinating her adult son’s care.

Ralph's story is illustrative of three points: that flexible supports not only may enhance choice but be cost-effective; the value of combining MassHealth and DDS resources; and, with flexible supports, funding needs to be flexible too as circumstances change over time.

In Massachusetts today, two people with the same level of need for ADL assistance may receive a different range of services. Ben (not real name) is 30 years old and entered a community residence near Springfield when he was 20 years old. The group home had an opening and the school system agreed to pay until he was 22 years old, as it had been paying for a residential school. Factors outside of public supports necessitated Ben's placement and fortunately the Commonwealth was responsive. Compare Ben's experience to Angela. Angela is in her late 20s and lives with her parents. She has a similar medical and supports needs profile as Ben. She receives continuous nursing and PCA services that include overnight positioning. Her parents have had Angela at home since infancy and wished to maintain her there until they feel they have to take the next step. A lack of staff (partially affected by payment rates for nursing and PCA) has triggered the need for DDS residential supports. Given Angela's need for nursing support, a small home with a high level of support is desired by her parents. The family hopes to find something reasonably close in geography with house mates close to Angela's age, but there are no homes available. If in-home staff via the Medicaid LTSS programs were consistent, her parents may have waited longer before seeking placement.

The use of AFC, PCA, and/or Family Supports can effectively address the needs of a significant subset of constituents while delaying the use of 24/7 supports. When these supports are disrupted they result in increasing 24/7 supports in the short-run or have people fall out of the continuum with deleterious impacts. People with disabilities who are on their own find it difficult to maintain a balance in their life due to the financial limitations in public programs and lower rates paid for the programs.

Based on outcomes and our experience, The Arc strongly supports the mix of residential supports offered by the Commonwealth. However, access to and the availability of these supports are limited by systemic capacity, education and information.

**Question 2. What types of services and supports best allow or assist individuals with disabilities to participate in daily activities and employment settings that are integrated into the community?**

There are nearly 20,000 (some duplicate count) constituents with I/DD served through day habilitation, employment and community based supports through DDS and MassHealth funding (9,900 in day habilitation alone). The need for these effective supports and services will continue for existing constituents and those in the future who graduate from special education. In Section II of this written testimony, progress on the 2008 plan is nominally reviewed noting some positive change and areas for improvement.

If state and federal authorities would support and allow, changes in our state plan program for day habilitation funded through MassHealth would further positive outcomes for day supports and employment can result. However The Arc would want to see those changes happen in the context of state plan services versus movement to waiver programs (with some modest exception).

We believe that the present mix of employment, community based day supports and MassHealth day supports are essential in the continuum. Significant progress could still result through reform in public and special education, higher education and the education of staff and stakeholders in newer technologies and tools. Discussion follows in Question 3.

**Question 3. Are there barriers that prevent or limit some individuals with disabilities from integrating into and living successfully in the communities of their choice?**

A major impediment to addressing choice and integration is the present delivery of special education and the lack of earlier intervention options for children and adolescents. A second major impediment is the lack of knowledge and newer techniques/tools on the part of all of our stakeholders, staff and systems managers across all sectors which support people with disabilities and elders.

*Need for additional forms of early intervention*

There is a preparation gap in public schools. For younger students, the lack of adequate interventions in social skills delays growth in other areas. For teens, there continue to be deficiencies in preparing students for more independence and real-time referral information for adulthood. Some school systems have recruited highly skilled transition staff and the placement of counselors in high schools by the Mass. Rehabilitation Commission (MRC) has improved capacity. Despite this, the knowledge and achievement gap has serious fiscal implications in supporting adults for the long-term.

Additionally, the Commonwealth's cities and towns do not *proactively* address children with complex behavioral needs during the grade school years. Students are referred to intensive out of district programs including residential schools. Consequently, strategies and programs do not develop locally. Students age out and require significant staffing for decades. Partnering on assessment teams to focus on effective strategies and offering adequate in-home supports are necessary to stem this tide of ineffectiveness.

These are generalizations. More than a decade ago, many school districts hired outside ABA consultants and others with expertise to address behavioral issues. But the *Rosie D.* case was still needed to address children "stuck" in hospitals and other restricted settings. This does not address the root problem adequately although it has improved outcomes for some. In Massachusetts, adults continue to age-out without appropriate alternatives, or very high cost interventions being required. The lack of an adequate workforce is another factor.

*Need for wider adoption of technologies*

Technological approaches need to be further utilized which can improve outcomes at a younger age. For example, there are devices that provide a warning when a student without verbal communication or the ability to express internal states is becoming anxious or agitated. Matthew Goodwin at Northeastern University developed technologies that notify teachers/parents of anxiety or stress so they can modulate their interactions. (Source: <https://www.ccis.northeastern.edu/corporations-industry/matthew-goodwin-bridging-disciplines-for-autism-care/>)

### *Personal, individualized services*

Keeping pace with the individualized nature of services and supports is difficult. There is a tension between this human fact and the need for structure within a system. Yet supports are essential for people with disabilities to thrive *and* survive in their communities. The need for and the nature of services may change over time for a variety of reasons including: illness, decline in functioning (temporary and permanent), reduced personal financial resources, changes in housing, and changes in family or other unpaid caregiver supports.

One device for individualizing I/DD services is utilization of self-directed services model. Because self-directed services were studied and found to be very cost effective and also result in higher quality of lives for individuals with I/DD, in June 2014 the Federal government issued instruction to states to require that every person receiving HCBS be offered the option to self-direct. As noted under Question 1 above, the most recent national data available on adoption of self-directed services shows that in Massachusetts, only 3% of adults with I/DD receiving services are utilizing this option. (Source: National Core Indicators, <http://www.nationalcoreindicators.org/charts/>)

### *Need for transportation*

The lack of adequate transportation is another major impediment for people with disabilities as a whole and for those with I/DD in particular. Improvements have been made but accommodations in respect to cognitive or intellectual disabilities lag. The ADA as amended affords certain rights in this area. The Rehabilitation Act of 1973, as amended, provides discrimination protection to people with disabilities, particularly in Sections 503, 504 and 508. People with disabilities are no longer to be excluded from, denied the benefits of, or be subjected to discrimination under any program or activity that either receives Federal financial assistance. (Source: <http://www.thearc.org/what-we-do/public-policy/policy-issues/transportation>) In 2015, National Council on Disability released a report reviewing the status of transportation accessibility. In the report release, Council Chair Jeff Rosen stated: "For Americans with Disabilities many transportation services remain stuck in neutral. For many Americans with Disabilities the prospects and possibilities for going to and from work, school and recreational activities are stuck in neutral." There were several key findings, including this on paratransit: "There have been great gains in best practices in the areas of eligibility, telephone hold time, on-time performance, no-show policies, and origin-to-destination service, but they are often not implemented." (Source: <https://ncd.gov/publications/2015/05042015/>)

### *Free and Appropriate Public Education*

Parents of children and adults with disabilities often experience barriers in securing an adequate education experience. The interaction between the caregiving role, public or other supports and the child's achievements are interconnected. These early interactions set a threshold for expectations and achievements. Barriers are often experienced in the areas below:

- Advising parents about their rights regarding child's education, especially families of cultural and linguist minorities
- Finding a pre-school that not only accepts the child but has skilled staff
- Developing or implementing an individual education plan that reflects the child's true needs
- Connections to a peer group for the child
- Obtaining help in community and travel safety

- Obtaining information or assistance in sexuality education
- Obtaining in-home support so that the caregivers can address medical or material needs

### *Health Care Access and Delivery*

Below we provide a longer response in relation to the Health Care system because the increasing control over our constituents' services through health plans and health entities (e.g., Accountable Care Organizations, ACOs) despite documented lack of knowledge of these systems regarding people with disabilities and particularly those with I/DD.

The lack of understanding of persons with I/DD in generic service systems continues to be a barrier. In 2005, the U.S. Surgeon General released a "Call to Action to Improve the Health and Well-Being of Persons with Disabilities." (Source: <https://www.ncbi.nlm.nih.gov/books/NBK44667/>) This followed a 2001 report focused on Intellectual Disabilities by David Satcher, the previous surgeon general. In late 2008, The Arc of Massachusetts with faculty and doctoral students at Boston University's School of Social Work released "Out in the Cold" which documented the barriers to quality health care for those with I/DD in Massachusetts. Results were published in a journal of the National Association of Social Work. (Source: <https://academic.oup.com/hsw/article-abstract/35/4/280/609917>)

The 2005 Surgeon General's report noted 4 national goals:

1. People nationwide understand that persons with disabilities can lead long, healthy, productive lives.
2. Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.
3. Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
4. Accessible health care and support services promote independence for persons with disabilities.

The reality is that managed care/integrated care strategies in health care (private or public) do not directly address the deficiencies discovered through these reports and other reports, such as the 2014 article on health and I/DD. (Source: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4098023/>)

All these reports concur there is a lack of knowledge and preparation of health care professionals. This results in inaccurate diagnoses and delays in treatment and intervention.

A lack of knowledge, along with bias (whether intentional or unconscious), can have disastrous effects. Such was the situation for Betty Ann Blake in 1998, who lay choking in a hospital overnight despite her parents and staff pleas for a proper evaluation of her throat. In 2001, Judge William Young (then Chief Judge, US District Court of Mass.) wrote in his opinion of the case, *Blake vs. Southcoast Health System*: "Behind the arid record of every legal case are genuine human beings with hopes, fears, aspirations, and an almost prayerful desire that sound laws will be wisely administered. Occasionally, though, there comes before the Court a situation evidencing such profound and shocking institutional incompetence leading to such unspeakable agony that the very stones of the courthouse would seem to cry out for relief." Perhaps this death is an outlier case but it reflects what can happen when professionals refuse to act properly due to a lack of knowledge and bias. A more recent case in the criminal justice system, the 2013 death of Ethan Saylor, a 26 year old man with Down syndrome who tried to remain in a movie



theatre without paying (he had just seen a movie and wanted to see it again). The theatre manager called for assistance and mall security guards used excessive force to subdue him, resulting in his death. In 2016, uninformed police response resulted in the shooting of Charles Kinsey, a mental health therapist, who was trying to help his 23-year old client with autism return to his day program. Thankfully Mr. Kinsey was only wounded.

Integration into our communities requires that professionals in all sectors (health care, legal, transportation, schools, etc.) understand and appreciate the diversity of those we support. The workforce crisis which exists means that people play caregiving or support roles on short notice and often without proper preparation. Any work we do in the broader community can only assist in improving the quality of those who work directly in our public service sector.

The lack of maintaining adequate rates over time has been a barrier despite the positive introduction of Chapter 257. State plan services have experienced rate setting delays for decades. When these rate delays are prolonged (e.g., continuous nursing), deterioration of the workforce becomes significant, requiring years to rebound. The loss of experienced staff means pressure to find new recruits in a shrinking workforce.

**Question 4. Should service and support systems in the Commonwealth be changed in order to promote, and increase opportunities for, community inclusion for people with disabilities? If so, how, and if you had to prioritize, which would be the most important?**

The Commonwealth should NOT sacrifice its Olmstead activities to address increasing costs in the Medicaid budget. The lack of progress in generic services and the negative impact on long term supports will multiply given the range of needs that exist and a shrinking workforce.

As we have noted in our testimony there are areas to improve while maintaining the framework of our safety net. The five areas which require action include:

- Support Families – Informal networks of support should be nurtured; a side benefit is that it reduces reliance on 24/7 supports.
- Technologies and innovative practices –
  - Complete the “Real Lives” and supported living transition – supported living options, family supports, DESE-DDS program, generic supports, employment-community volunteering, agency with choice, participant directed options including the PCA programs, AFC, shared living, etc. Ensure that information sources are aware of all the options.
  - Utilize technology in various ways including assisting with behaviors, reducing staff in 24/7 or related services, helping independence with guide tools in community travel, teaching tools and reminders. Ensure adaptive equipment is universal for those with physical and cognitive impairments. Expand the use of dedicated and non-dedicated devices as in “autism omnibus bill” and wider adoption of tele-health.
- Proactive action including improving outcomes in school systems – Early Intervention programs as of 2015, served 15,000 infants and toddlers. Track children effectively to know when more

assistance is needed-perhaps through a hotline that families can call when behaviors or medical conditions (latter has a better system of support) become more complex. Develop assessment teams that aren't reliant on a type of service, e.g., day or residential school, but allow for a full assessment and as in the DESE-DDS program. Provide supports with knowledge that costs of support will be lower in the long run. Ensure schools are preparing children for the long-term.

- Workforce – Keep pace with reasonable cost adjustments including addressing benefits. Use of technology and supporting families should help to address high staff demands of future. Better transition support will reduce staff needs too.
- Self-advocacy - Teach students to self-advocate and introduce them at an early age to be involved in decision making about their lives. Assist them to participate in self-advocacy organizations.
- Community education and partnership with statewide advocacy organizations – Develop statewide public education campaign targeted at various staff sectors and the constituents themselves. Develop a five-year campaign to address bias and increase acceptance and understanding.

**Question 5. Bullying poses a problem for vulnerable tenants in some public and subsidized, multi-family housing. What are some policies, practices or other solutions the Commonwealth should consider in order to address this issue?**

Bullying is common in schools and communities in addition to impacting tenants in public housing. Public education noted in #4 is one tactic. But in specific settings, identified leaders should be enlisted to assist in this process. These nominal leaders should be given support by the official authority or landlords in tangible ways to reinforce the positive approach. Severe penalties for repeat offenders should be a last resort but concern here is retribution to those with disabilities if offenders return to project even temporarily. National organizations such as the Southern Poverty Law Center are offering free resources for increasing understanding and tolerance and reducing bullying. See the Center's Teaching Tolerance website and resources at: <http://www.tolerance.org/>.

## **SECTION II: 2017 Review of the 2008 Olmstead Plan**

Since 2008, some needed change has occurred. Below is The Arc's opinion of progress made toward the 6 goals.

### **Goal 1. Help individuals transition from institutional care**

Progress continued in this area. The Commonwealth committed to the remaining consent decree members that one facility (Wrentham) would remain open during the members' lifetimes. We expect the Hogan facility census will decline further and setting will have to be closed. Under no condition would The Arc support the admittance of new residents at either facility. Over time Wrentham will need to be re-configured as census decreases.

Related to deinstitutionalization is the need for health care in the community. Although Massachusetts has expanded health insurance coverage to most of the population, our constituents receiving MassHealth experience barriers as noted due to lack of knowledge and resulting bias. Other examples of limitations or barriers include:

1. Inadequate number of primary care practitioners (PCP) for adults with disabilities
2. Inadequate number of PCPs and certain specialty care (e.g., neurologist, neuro-psychologist, etc.) who will accept Medicaid (this includes the time it takes for those without verbal communication and/or behavioral conditions)
3. Inadequate supply of dentists, dental care for constituents with moderate to more severe impairments often supplied through Tufts Dental and other partners (MassHealth funding and time for interventions is a big factor)
4. Need for further accommodations for testing devices or tools to insure accurate health assessments

## **Goal 2. Expand access to community-based long-term care supports**

The implementation of the autism omnibus bill opened the door to more coordinated services for adults with autism, Prader-willi and Smith-magenis syndrome who have developmental disabilities. MassHealth improvement for dedicated and non-dedicated devices and BCBA supports were positive developments.

The state chose not to adopt the state plan option K (Community First Choice) for personal attendant services – this was a disappointment. At the time, it would have provided 6% more in federal reimbursement and assisted those who need prompting and cueing for activities of daily living (the 6% add-on was repealed within the past three years by Congress).

The decision to pay personal care attendants overtime when working over 40 hours for two or more recipients will reduce PCA availability. Since unlimited overtime is not possible, given the hourly rate paid to PCAs, the attendants will still need 2<sup>nd</sup> jobs for economic reasons and will seek them elsewhere. New attendants need to be trained and obtained. In addition, there is a fear that there will be further encroachment by state officials in the future on the independence of recipients to manage as they wish given its acceptance of certain third party status.

## **Goal 3. Improve the capacity and quality of community-based long-term supports**

At the Federal level we now have the revised rule for Medicaid-funded home and community based services (HCBS). Known as the HCBS Community Rule, people receiving HCBS-funded services must receive person centered service planning and live and spend time during the day in settings that ensure a person receives services in the community with the same degree of access as individuals not receiving HCBS.

Massachusetts is making progress on these but has not shared settings compliance for people with I/DD with the stakeholder group in some time. With the push back for settings compliance an additional 3 years, to 2020, this means less pressures to transform day programs, group homes and assisted living settings to be less institutional and more what these revised rules require, an integrated life with access to greater community, with opportunities to work in competitive integrated settings, to engage in community life, and control personal resources.

Passage of the “Real Lives” bill helped to place expanded choice in statute for HCBS. But progress on the ground was slow. National Core Indicators (NCI)<sup>™</sup>, a voluntary effort by public developmental disabilities agencies to measure and track their own performance, has valid and reliable data about the performance of public developmental disabilities service systems. The most recent Massachusetts NCI data posted (2013-14) show that only 3% of adults are utilizing any kind of self-directed service option.

DDS’ adoption of Positive Behavioral Supports provides a new threshold which agencies have to meet in serving those with disabilities. Leaders at provider agencies have cited that this adoption, through requiring additional committees and effort, has resulted in improvement of service delivery.

The passage of federal background checks and their implementation for those served by the Department of Developmental Services will allow the state to further protect recipients from those involved in felonies in other states who seek employment. Work has been in progress on a registry bill for those who have substantiated investigations for abuse which don’t rise to court involvement. We appreciate state officials’ work on both of these activities.

The implementation of Chapter 257 was a positive development during the period resulting on regular rate reviews to address actual costs in service delivery.

#### **Goal 4. Expand access to affordable and accessible housing and supports**

Access to affordable and accessible housing has been a long-standing barrier for people with I/DD and elders, and remains so. As our population ages, this dearth of housing will be even more problematic.

Our state Olmstead plan called for EOHHS to collaborate with the Department of Housing and Community Development to expand affordable housing and develop and renovate housing stock to increase accessibility. EOHHS also planned to raise the public’s awareness of accessible housing through promotion of the MassAccess housing registry.

The lack of major federal and state increases for housing vouchers combined with the high cost of housing in Massachusetts means this goal was not substantially achieved. It also means higher public outlays for group living. In addition, economic factors are negatively impacting our lower income population. The 2015 Greater Boston Housing Report Card noted, “Almost 172,000 people moved into the region between 2010 and 2014, yet only 15,000 new houses, condominiums and apartments were built. To find out why supply has stubbornly been unable to meet demand year after year, the authors collected and analyzed cost data from developers and housing agencies. Their conclusion is very

unsettling: the numbers just don't add up. Land, construction and development costs in Massachusetts are so high and zoning against high-density developments is so pervasive that builders simply can't produce housing that working and middle-income families can afford. Virtually all new low-density projects cater to the high end of the market." (Source: <https://www.tbf.org/~media/TBFOrg/Files/Reports/GB%20HousingReportCard%20111315.pdf>)

### **Goal 5. Promote employment of persons with disabilities and elders**

The Department of Developmental Services (DDS) has put tremendous effort into closing segregated work programs and promoting paid, integrated employment for people with I/DD. Other state agencies too have made commitments, such as Mass Rehabilitation Commission's placement of an employment resource worker in every high school to counsel students with I/DD on job placement and work experience while in high school. Although systemic change is underway, adults with I/DD are still woefully underemployed. Funding employment and day support staff has not kept pace with the changes. The most recent Massachusetts National Core Indicators data (2015-16) regarding adults receiving services from DDS shows both progress and room for improvement. (Source: <http://www.nationalcoreindicators.org/>)

30% - The proportion of people who have a job in the community.

45% - The proportion of people who do not have a job in the community but would like to have one.

27% - The proportion of people who have a goal of integrated employment in their individualized service plan

### **Goal 6. Promote awareness of long-term care supports**

Family support programs, independent living centers and DDS service coordinators provide a doorway for awareness of long term supports. However, a lack of knowledge within our school systems means that many families and self-advocates do not learn about the range of services available. The growth in AFC providers means that some individuals may learn about a particular service more quickly, and though positive, the information provides only a partial picture. More energy on public education continues to be needed not only in regard to public resources but partnership strategies with private funds, and legal and financial planning.

In legal planning, families do not realize the continuum of protective devices that can be used such as health care proxies, power of attorney, supported decision making, trusteeships, and other approaches to avoid guardianship or other extreme forms of control.

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