

# Response Form

Issued: April 16, 2021

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## Respondent Information Cover Sheet

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Include the following information for the individual who should be contacted for purposes of discussing any aspect of the Respondent's completed Response Form:

**First Name:** [Leo]

**Last Name:** [Sarkissian]

Maura

Sullivan

Ellen

Taverna

**Title:** [Executive Director] **Organization:** [The Arc of Massachusetts]

**Respondent Principal Address:**

[217 South Street]

[ ]

**City:** [Waltham] **State:** [MA] **Zip:** [02453]

**Telephone:** (781 891 -6270 **E-mail:** [sarkissian@arcmass.org]

**URL:** [thearcofmass.org]

- **I am responding to this RFI on behalf of the Organization listed above:** Yes: [X] No: [ ]
- **The information in this response is my own individual opinion:** Yes: [ ] No: [X ]

**Total pages in the response (including cover sheet):** [8]

**Response to RFI Questions:** #1-#4

**EOHHS Request for Information:** Enhancing, Expanding and Strengthening Home and Community Based Services in Massachusetts using American Rescue Plan Act Section 9817 Funding

Respondent Name: [ Maura Sullivan ] Organization (if applicable) [The Arc of Mass]

Response to: **Topic Area #** (see page 6 of RFI): [#1]

Short title that briefly describes your proposal: [Enhancing access to HCBS for people with autism and I/DD and their families]

Program(s) and/or service (s) impacted: [Family Support, PCA, AFC, Day Habilitation, Transportation, Shared Living, Self Direction and Healthcare]

Investment type:  One-time  Short-term (less than 12 months)  On-going

Estimated investment: \$[97,000,000]

***Describe your proposal below.***

The Arc of Massachusetts requests the following ways of utilizing the available funds through ARPA Section 9817 to enhance, expand and strengthen HCBS activities.

The Arc requests an initiative to increase access and opportunities for more flexible family supports for the 20,000 families currently serviced and underserved through DDS. Funding allocated to families would prevent further housing and food insecurity. This assistance will help stabilize families as in-home and community supports begin to return to pre-covid-19 status. Families need recovery from lost wages, missed work opportunities and assistance to “get on their feet” to move forward.

Individuals with autism and I/DD need more support through PCA and AFC services to address regression or stalling of skills. Prompting and cueing for PCA and AFC services must be allowed for progress for individuals toward increased independence and dignity as well as health and wellness/hygiene and activities of daily living. Physical assistance should not be the main factor in supporting activities of daily living. We request an approval of prompting and cueing in PCA time approvals, especially considering those who have lost out on these needed supports during covid-19.

We are requesting other services be made available to support those at home include Applied Behavior Analysis (ABA) for adults who rely on MassHealth for coverage. Throughout the pandemic even virtual supports were not available for adults with severe behavior challenges or for those who developed new maladaptive behaviors due to the change in structure, the limitations of the pandemic and the lack of overall supports available (day programs, employment, recreation, social etc.).

Additional services should address the lack of communication supports available for those at home. Lack of Augmentative, Alternative Communication (AAC) expertise is causing frustration, challenging behavior, increasing isolation, anxiety and depression. We encourage a plan that will increase access to AAC services including more ongoing training for individuals, their workforce and family caregivers.

As the state begins to fully reopen Day Habilitation services, now is the time to invest in pilot programs that address the barriers to inclusion in the community. Pilot programs should focus on meaningful inclusion opportunities and the individual needs of those served. There should be enhanced funding to provide safe and accessible transportation while continuing to provide both rehabilitative and habilitative integrated programming. Without equitable pay for the direct support workforce, these meaningful inclusive opportunities will not be equitable. Some will need more supports, and this will require fully staffed programs with less turnover.

More incentives to encourage Shared Living, AFC and Self-Directed services could begin to address the concerns around the lack of options for person centered programming. Increasing AFC rates will allow providers to offer stipends that would encourage family members to consider caregiving through AFC. Without increases to the caregiver stipends, this care model is at risk. Across the nation, the pandemic has made the value and contributions of caregivers clear. Without our family caregivers, the direct support workforce crisis will become even more daunting. Low pay for AFC and direct support professionals will prevent access for individuals to all needed services because they will not be able to hire, fill their hours or obtain the assistance needed.

The state depends on older caregivers to support thousands of individuals with autism or I/DD. Without a focus on planning and transition, we will face an additional crisis of housing, direct support and living arrangements. There is a growing need to supplement current supports and transition to new living arrangements for individuals and older caregivers.

Lastly, adults with disabilities face significant access issues related to health care. Lack of access to primary and specialty care results in more health disparities, more hospitalizations and more institutional setting placements. To obtain equity and access in healthcare for people with autism and I/DD we must provide more training and support for healthcare providers through programs like Operation House Call.

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<b>EOHHS Request for Information:</b> Enhancing, Expanding and Strengthening Home and Community Based Services in Massachusetts using American Rescue Plan Act Section 9817 Funding
Respondent Name: [Ellen Taverna      Organization (if applicable) [The Arc of Massachusetts]
Response to: <b>Topic Area #</b> (see page 6 of RFI): Technology & Infrastructure
Short title that briefly describes your proposal: [Address Digital Divide]
Program(s) and/or service (s) impacted: [All]
Investment type: <input checked="" type="checkbox"/> One-time <input type="checkbox"/> Short-term (less than 12 months) <input checked="" type="checkbox"/> On-going
Estimated investment: \$[4,770,000; \$1,400,000] estimate 2 reflects ongoing initial years
<p style="text-align: center;"><b><i>Describe your proposal below.</i></b></p> <p>We are requesting the Commonwealth advance access and opportunities to supportive technology for people with I/DD and autism by embracing the “Technology Forward” plan written by the Massachusetts Innovation and Technology Task Force (Task Force).<sup>[1]</sup> The Task Force is a partnership between the Department of Developmental Services (DDS), Massachusetts Association of Developmental Disabilities Providers (ADDP), and The Arc. Supportive technology, which includes Assistive Technology, and Remote Support Technology, refers to devices and technological methods used to increase community integration of individuals with disabilities. Utilizing a person and family centered approach, supportive technology can be instrumental in assisting individuals with I/DD and autism attain the highest quality of life possible and promote the use of HCBS.</p> <p>Yet, studies show that people with disabilities have been left behind in the digital age and are using digital technology at a lower rate. According to a 2016 Pew Research Study, one-in-four disabled adults say they have high-speed internet at home, a smartphone, a desktop or laptop computer and a tablet, compared with 42% of those who report not having a disability.<sup>[2]</sup> In 2013, the Coleman Institute for Cognitive Disabilities released a Declaration of Rights, which has been endorsed by 645 organizations, affirming disabled individuals have an equal right to technology and information access. The Declaration states that inclusion itself is limited by the lack of technological access. Today much of our learning, working and connecting is dependent upon the internet and has altered how people acquire, utilize, and disseminate knowledge and information. Increasing access to supportive technology is key in creating equitable opportunities in society for disabled individuals.</p> <p>The Task Force identified the following impact areas where the Commonwealth should focus on expanding supportive technology to advance HCBS:</p> <ul style="list-style-type: none"><li>• <b>Communication:</b> Strategies and tools exist through assistive technology to enable many constituents served by DDS to verbally express their needs or preferences who could not do so otherwise. For example, an increase access to augmentative and alternative communication devices for people with I/DD in residential settings and day and employment programs could provide more opportunities to demonstrate independence and self-determination.</li><li>• <b>Turning 22:</b> The turning-22 transition process could be greatly facilitated by using technology to help individuals (and families) plan for adult life. Most striking is the drop in the ongoing support and utilization of technology from school to adult services. For those entering the workforce, technology could be pivotal in providing more meaningful employment as well as</li></ul>

supporting real-time training and job coaching. This remote assistance does not require the physical presence at an employment site helping alleviate the direct support workforce demand while at the same time improving an individual's level of autonomy.

- Residential demand: The Commonwealth is facing an increase in graduating students with I/DD and autism each year combined with the growing number of aging family caregivers who need more options to support their disabled family member. The expansion of supportive technology could be a cost effective, high quality innovation to provide person centered support HCBS options other than 24/7 congregate settings. For example, incorporating smart-home features in the home can assist with activities of daily living (ADLs) and reduce caregiver support.
- Employment and Community Inclusion: Individuals are challenged with securing competitive employment that maximizes their skills and allows for advancement and sustained employability. Using readily available supportive technology to increase self-management of tasks and job performance would be beneficial in enhancing equity for individuals with disabilities in the workforce and in their communities.

The COVID-19 pandemic has illustrated supportive technology's potential in bridging the access issues across healthcare, education, employment training and social connections, as well as helping to lessen the impact of social isolation, service interruption and caregiver burden. It is critical that individuals with I/DD have the resources and tools (e.g., high-speed internet, smartphones, tablets, and laptops) to access the internet to stay virtually connected. The pandemic forced Massachusetts service providers to enter virtual programming rapidly with little preparation or training, highlighting the necessity for a thoughtful and strategic approach to technology to create efficiencies and increase effectiveness of DDS supports and services. Using the ARP funds to invest in a supportive technology plan will increase the independence of people with I/DD and autism, bring a focus on human and civil rights regarding communication and preferences, help to address the workforce shortage in the wake of the pandemic and secure HCBS integration in communities across the Commonwealth.

<sup>[1]</sup> "Technology Forward, A Report Written by the Massachusetts Innovation and Technology Task Force." Available by request from The Arc of Massachusetts.

<sup>[2]</sup> Found at <https://www.pewresearch.org/fact-tank/2017/04/07/disabled-americans-are-less-likely-to-use-technology/>.

**EOHHS Request for Information:** Enhancing, Expanding and Strengthening Home and Community Based Services in Massachusetts using American Rescue Plan Act Section 9817 Funding

Respondent Name: [Leo Sarkissian] Organization (if applicable) [The Arc of Massachusetts]

Response to: **Topic Area #** (see page 6 of RFI): [#3 Promotion of HCBS]

Short title that briefly describes your proposal: Advance Understanding & Impact Generic Resources

Program(s) and/or service (s) impacted: [All]

Investment type:  One-time  Short-term (less than 12 months)  Longer term- 3 years

Estimated investment: \$750,000.

***Describe your proposal below.***

We continue to have elements within and outside our community advance separate or segregated options for persons with disabilities despite demonstrated advancements, e.g., persons able to successfully work, use properly adapted transportation, and communication with assistive devices. We also have seen individuals with significant intellectual impairment improve social and other skills by being included in ‘typical’ classrooms, social settings and after school activities. Despite this reality, we continue to segregate.

A story that reflects failure based on segregation is a young person not receiving adequate supports at home, including after-school ABA training, who transitions into residential school at 14 years old. Most likely the student will continue in residential for the next 55-65 years of his life at significant cost to the Commonwealth.

On the other hand, one recent success story is the engagement of 1,875 individuals/families in a Facebook group, which focuses upon higher expectations for individuals with disabilities in employment and other areas of life. This federal funded, DDS initiated collaboration (The Arc, ICI, DESE, Mass Fam, others) advances better practices and encourages growth. Individuals not only benefit, but over time the costs of services to individuals participating will be impacted due to furthering independence and communication.

We require a working committee to report to the administration and legislature, which will develop a plan to further move our society to full community inclusion. Target areas will include:

1. Transportation system (mass and regional),
2. Housing -affordable and accessible,
3. Recruitment and Orientation program for individuals who will join the workforce that focuses upon skill attainment, social relationships, and inclusion,
4. Collaborative social media campaign to help advance independence and inclusion among families and individuals.

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<b>EOHHS Request for Information:</b> Enhancing, Expanding and Strengthening Home and Community Based Services in Massachusetts using American Rescue Plan Act Section 9817 Funding
Respondent Name: [Leo Sarkissian/Ellen Taverna] Organization (if applicable) [The Arc of Mass.]
Response to: <b>Topic Area #</b> (see page 6 of RFI): [ #4 HCBS Workforce ]
Short title that briefly describes your proposal: [Addressing HCBS Adequacy & Inclusion]
Program(s) and/or service (s) impacted: Range of HCBS Services for Persons with I/DD
Investment type: <input checked="" type="checkbox"/> One-time <input type="checkbox"/> Short-term (less than 12 months) <input checked="" type="checkbox"/> On-going
Estimated investment: \$322,650,000 – year one

***Describe your proposal below.***

We encourage the Administration to increase the direct support professional (DSP) wages and benefits based on market-based reimbursement rates in the Commonwealth to support more HCBS opportunities for people with disabilities. This will require a multi-year investment. There is a direct support workforce crisis that has been compounded due to the COVID-19 pandemic. The work that DSPs do is invaluable to the I/DD community. The DSPs and their supervisors can keep people out of more costly, restrictive, and often segregated institutional settings. But they require skills and professional training. Presently their compensation is equal to laundry workers and drivers. Yet they serve as the linchpin for success for so many people with disabilities to live the independent life that they choose in their communities with their friends and family. Often the greatest challenge in achieving integration at this time is the increasing lack of a direct support worker pool, adequate in capacity and skill. In addition to DSPs, compensation to clinicians, supervisors and program directors falls below comparable pay in education and health care settings.

Like so many families desperate for assistance, Gail Frizzell describes her daughter’s struggle to finding a direct support worker. “She’s been trying to fill one part-time position for over two years now. In the last 10 months, she’s had one applicant, who didn’t show for the interview.... I’m very afraid for her. I will be with her to love and support her for as many years as I am able, but after years of abusing my body in order to care for hers, I can no longer provide her physical care either. Lauren needs well trained, caring support staff in order to survive. Her hard-won independence is about to fall apart and I don’t know what the alternative will be. Whatever it is, it won’t be her choice.”<sup>[1]</sup>

DSPs are disproportionately women of color, doing critical tasks that support people with disabilities with taking medications, bathing, eating, getting out into the community, and more. It is difficult work that requires thought, planning and communication skills as well as understanding ethical principles and practices of inclusion. Often it can be physical—requiring significant effort around activities of daily living. It is about active caregiving. Today’s laws and regulations which focus on self-determination, inclusion and community integration require staff who are competent and prepared, but the wages do not reflect this level of skill. Due to low wages, there is an approximate 50% national turnover rate annually, and the average national wage is less than \$11/ hour, making it difficult to provide continuity in services, provide a family sustaining wage, and threatening the quality of care.

There are three categories of DSPs: provider agency which include clinicians and supervisory staff roles;

independent DSPs working in self-direction, supported living and PCA services; and caregivers funded by stipends (primarily AFC). The rates service providers receive to ultimately pay DSPs do not consider the wages of competing occupations, the need for benefits, and the actual costs of services. What has resulted are rates and therefore wages that have been flat for decades, without even cost of living increases. Meanwhile, the Massachusetts minimum wage will rise an additional 11% over the next two years and the Commonwealth is reported to be the third most expensive place to live in the nation. The broad market to which DSPs can seek alternative employment needs to be considered. Over the past six months, workers in other industries have been successful in increasing their compensation. For example, delivery drivers and grocery store workers are starting at higher salaries than DSPs.

This investment in the workforce also includes AFC family (and non-family) caregivers of people with disabilities who have spent the past year without their lifeline supports in their homes and in the community due to the pandemic. AFC caregivers have stepped up to provide 24/7 supports including managing challenging behaviors, personal care, feeding, virtual learning and even nursing tasks. Increased funding in respite and family support would go a long way in assisting exhausted family caregivers.

We recommend a two-year strategy to increase compensation annually by 11% (8% required allocation for personnel). In a longer format, we can share how this investment with other changes can result in lowering the rise in service costs over a multi-year period.

The Commonwealth must ensure the stability, health, and well-being of individuals with I/DD. The ARP funding would be a jumpstart more equitable rates to recruit and retain a qualified workforce to deliver quality services.

<sup>[1]</sup> Gail Frizzell, “The Direct Support Workforce Crisis: A Parent’s Perspective – Part I”, December 24, 2015, found at <http://www.eparent.com/eparent-connect/parenting-2/the-direct-support-workforce-crisis-a-parents-perspective-part-one/>.