ADDP Association of Developmental Disabilities Providers

Community for Living. Community for Life.

Interim Day Habilitation Service
November 13, 2020

Introduction

When the COVID-19 pandemic initially became acute in March 2020, an Executive Order was issued by Governor Baker to close day programs during this declared public health emergency. As positive COVID rates decreased and the State began its re-opening phases, day programs were able to open in late July - August at approximately 40-50% of their normal program capacity due to social distancing requirements. Recognizing how destabilizing these conditions were for day service programs, retainer payments and enhanced rate provisions were made to providers in an effort to preserve the Day Services system. Despite the fact that COVID-19 remains an ongoing threat for at least the remainder of the current fiscal year and possibly longer and with a resurgence of infections, enhanced rate payments are projected to stop on November 30, 2020.

Outlined below please find an overview of the Day Habilitation service delivery model, a description of alternative models to consider during the pandemic, the potential impact of the termination of rate enhancements on day habilitation programs and on individuals no longer receiving these services, and the need to stabilize the Day Services system for the future.

Model Overview

A Day Habilitation service is a model for members with intellectual and developmental disabilities in need of therapeutic interventions and medical oversight. These services are best delivered in-person at a Day Habilitation facility where a multi-disciplinary team approach can be implemented with access to professionals (such as Physical Therapists, Occupational Therapists, Speech Pathologists and/or Behavior Therapists) and equipment.

It is necessary for individuals and families to have access to this entitlement service, especially during the pandemic, and to make informed choices about the risk and benefits of receiving Day Habilitation services. When assessing risk during COVID-19, providers may use the designated EOHHS risk benefit tool to work with members to determine the best service delivery method. This may include selecting from a menu of service delivery approaches (some of which are modified or temporary) to re-engage or admit new participants into this service. Educating members, families, and support staff about these options is an important step in providing flexible and responsive supports for each person's unique circumstance while ensuring their health and safety. This process includes consideration of a participant's service goals and needs and the provider's ability and readiness to deliver the various interim service types.

Providers will vary in the services they can offer based on many factors, such as funding, service cost, staff availability, facility capacity, transportation, socioeconomic resources, technology, ability to meet the CDC guidelines, and family and congregate care site's willingness to open their homes for day services. **It is expected that service delivery must be flexible over time due to these variables, as well as the unique needs of members and providers**.

Alternative Service Delivery Models

All proposed service models are intended to be delivered to the participant through in-person or remote/virtual support. **The different service options are intended to be flexible with the ability to combine service approaches**. Based on the options selected, participants may see a reduction in service delivery hours to meet their needs and the social distancing capacity restrictions of providers. The service delivery model will be determined by member choice and the provider's ability to provide services in the delivery approach selected by the member/family.

The menu of support described below is intended to be a method to deliver the scope of services as defined in the Day Habilitation program regulations (419.421) during the pandemic. This includes developmental skills training as defined in the regulations as a "series of planned, coordinated and goal-oriented services," such as self-help, sensorimotor, communication, social skills, independent living, affective development, behavior, and wellness. Flexible supports are based on a service needs assessment recommended by the interdisciplinary team. When it is not possible to deliver services recommended, the team will work with members on methods that reduce risk of decline and increase access to opportunities in the program's eight service need areas. Also, during this interim time, services provided will work to maintain oversight, relationships, and connections to ensure a smooth transition when members are able to access or return to this service.

The unbundling of services into discrete parts will disrupt the current integrated service and cost model that is at the core of the current Day Habilitation service delivery model. The most effective and efficient manner to deliver these services is through a facility-based Day Habilitation model that offers high quality services, with full oversight of the therapeutic, programmatic, and clinical/medical team. **The challenge of implementing these interim service delivery recommendations is aligning a cost model that will reimburse providers to deliver one-to-one staff to client services.**

The flexibilities described below are intended as an interim support to prevent member decline and allow providers to assess best practice and increase access to service while placing health and safety at the forefront.

Day Habilitation Services, either in person or remote, must include the scope of services as defined in the program regulations in section 419. 405. This includes nursing services and health care supervision, developmental skills training, therapy services, assistance with activities of daily living, and service management.

The core professional team described in section 419.421 of the regulations is the health care supervisor, service manager, director, and developmental specialist. This team is responsible for the oversight of a service delivered in any of the four methods described.

Additional team members may be included as needed: Physical therapist, occupational therapist, speech and language pathologist, and behaviorist. As noted in MassHealth Day Habilitation Bulletin 12, for interim

purposes, the director or service manager may approve service plans and complete service needs assessments with consultation from the core professional team.

These services have the flexibility to be delivered in any of the four methods described below: Provider site (in person), offsite (in person), virtual/remote, and telephone.

Provider Site (In Person)

The on-site service option at the provider site is the preferred method for service delivery as it allows for optimum oversight, coordinated care of service delivery, and efficiencies. In some cases, a provider may serve members at a different location or site that is not the member's primary pre-COVID site. Change in the provider site location could be due to COVID-related implications, such as program consolidation, staffing, accessibility, transportation, and/or provider financial stability.

On-site services have capacity limits based on the need for social distancing. This means that all members may not have on-site services available to them or may have reduced access to this option. On-site services may be dependent on reported positive COVID rates, access to transportation and personal protection equipment, and other safety related complications.

People utilizing this support will need to be aware of the CDC guidelines, such as social distancing, wearing personal protective equipment, and good hand hygiene. This support is for members who need traditional daily support due to caregiver, social and behavioral, and/or learning needs.

In this method, services will be provided by the professional and paraprofessional staff. This service delivery can also supplement other service delivery methods.

On-site services offer the traditional service delivery method to members; however, it will be designed to also ensure health and safety during the pandemic. This may require increased staff-to-client ratios to allow for cohort development, supervision, and education in wellness and hygiene. Activities will include any service delivery within the scope of Day Habilitation as described in the regulation in 419. 405.

Off-Site (In Person)

Off-site service delivery is best suited for members who need in-person supports for health and safety. This service can be provided in the members' home or in the community by either one-to-one staff/client ratios or in a small cohort. This support is also available to members living in a residential or group home setting who require therapeutic services not available in the home.

Services will be provided by the professional and paraprofessional staff. This service delivery can also supplement other service delivery methods. Activities include any service delivery within scope of Day Habilitation as described in the program regulation (419. 405). This off-site approach can be combined with other service delivery approaches.

Examples of off-site, in person service:

- Treatments prescribed by the member's PCP
- Education in hygiene and health concerns
- Monitoring member's health status
- Oversight of therapy as recommended by a licensed therapist

- Coordinating care and activities of daily living (ADLs)
- Nutritional supports
- Care giver support
- Expressive language supports and non-verbal communication
- Leisure and recreational skill building
- Household skills development
- Decision making, emotion expression
- Behavior supports
- Conducting mental and emotional wellness checks and supports
- Employing interventions to promote individual orientation of person, place, and time
- Monitoring and encouraging progress toward individuals' service plan goals
- Providing caregiver support, especially informal caregivers and members with dementia, as well as supplying Positive Behavior Support strategies
- Providing members and their families with language and interpretation supports
- Group activities led by a staff person with a specific objective of goal for member
- Health and wellness education
- Coaching in exercise and/or mobility and range of motion exercises
- Identifying and addressing any declining health conditions
- Identifying and addressing any nutritional needs or deficiencies
- Monitoring, managing medications, treatments, and durable medical goods

Virtual/Remote (Using remote communication tools, including Skype, Zoom, Apple FaceTime, Facebook Portal, or related streaming service)

Virtual service delivery will be available to members who have personal access to technology (Wi-Fi and hardware). This option requires members with ability to access technology independently or through a caregiver at home. Virtual supports are best for individuals who may have significant health risks or are uncomfortable accessing group and community settings as a supplement to traditional in-person services. Remote service can also supplement supports provided through the other service models and when there is gap in in-person service delivery due to COVID-19.

This service delivery can also supplement other service delivery methods. This service delivery option can be in group format or one-to-one staff support based on member need. While this method can be effective for some members, many members need additional assistance from either home supports or additional Day Habilitation staff for trouble shooting, attention redirection, scheduling support, and navigation.

Services will be provided by the professional and paraprofessional staff. Activities include any service delivery within scope of Day Habilitation as described in regulation 419. 405.

Examples of virtual/remote service:

- Conducting mental and emotional wellness checks and supports
- Employing interventions to promote individual orientation of person, place, and time
- Monitoring and encouraging progress toward individuals' service plan goals
- Group activities led by a staff person with a specific objective of goal for participant
- Health and wellness education
- Coaching in exercise, mobility and range of motion exercises

- Social and communication skill building
- Leisure and recreational skill building
- Household skills development
- Decision making, emotion expression
- Behavior supports

Telephonic Service Delivery

Telephonic service delivery will be available to members and their caretakers to deliver services for members who prefer phone communication and lack technology accessibility, skill, and/or support. Telephone supports are best for individuals who may have significant health risks or are uncomfortable accessing group and community settings. This service delivery can also supplement other service delivery methods.

Services in this model are delivered, as needed, by interpreters or professional staff members as described in the Day Habilitation program regulation (419.421), which include administrator, program director, health care supervisor, developmental specialist, service manager, other licensed nursing staff, other direct care staff (paraprofessionals), behavior professionals, and therapists. It can be delivered in a group format or one-to-one support based on the member need. This delivery method is essential for privacy health related information and person specific needs that may require one-to-one support.

Activities include any service delivery within scope of Day Habilitation as described in regulation 419. 405.

Examples of telephonic service:

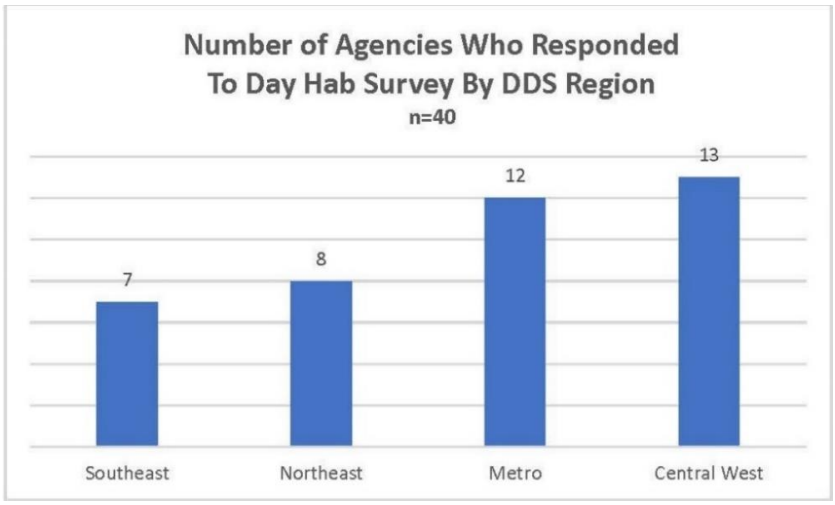
- Coordination of each member's DHSP with other health care professionals including the NF where the member resides
- Health and wellness education
- Monitoring each member's health status
- Care Giver Support and care coordination
- Reporting changes in the member's condition to the member's PCP
- Oversight of therapy treatment as recommended by a licensed therapist
- Assisting members to make social connections with friends and family
- Conducting mental and emotional wellness checks and supports
- Employing interventions to promote individual orientation of person, place, and time
- Monitoring and encouraging progress toward individuals' service plan goals
- Providing caregiver support, especially for informal caregivers supporting the individual and caregivers supporting members with dementia, as well as supplying positive behavior support strategies
- Identifying and addressing any declining health conditions
- Identifying and addressing any nutritional needs or deficiencies;
- Appropriately monitoring, managing and refilling member medications
- Providing members and their families with language and interpretation supports
- Coaching and reminders of mobility and range of motion exercises
- Social and communication skill building
- Expressive language, choice making and emotion expression
- Monitoring, managing medications, treatments and durable medical goods

ADDP Provider Survey – Program Closures

In late September, ADDP requested its Day Habilitation provider members to complete a survey on the status of their Day Habilitation programs since they were not close to reaching projected capacity and many organizations were evaluating continuation of this service given the current rate enhancement was scheduled to end November 30. The survey includes three sections: Demographic information, potential closures, and caregiver capacity.

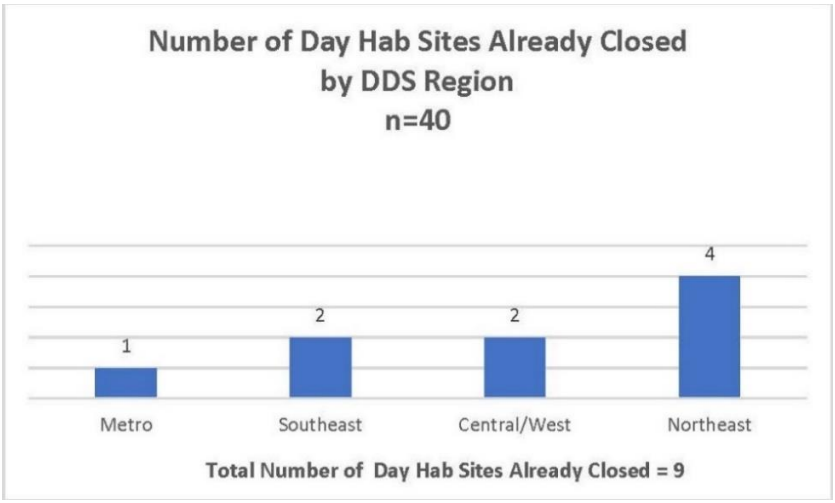
Demographic Information

Responses were received, over a one-week period, from 40 providers representing all DDS geographic regions (see chart below). The survey response rate included 75% of ADDP Day Habilitation members. Across all respondents, they reported operating 105 sites prior to the COVID-19 pandemic.

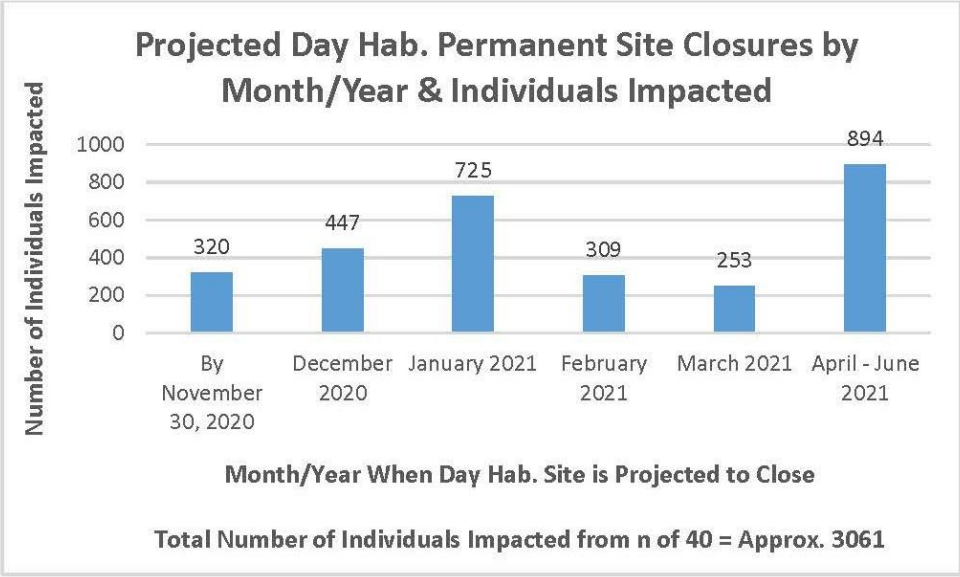


Potential Closures

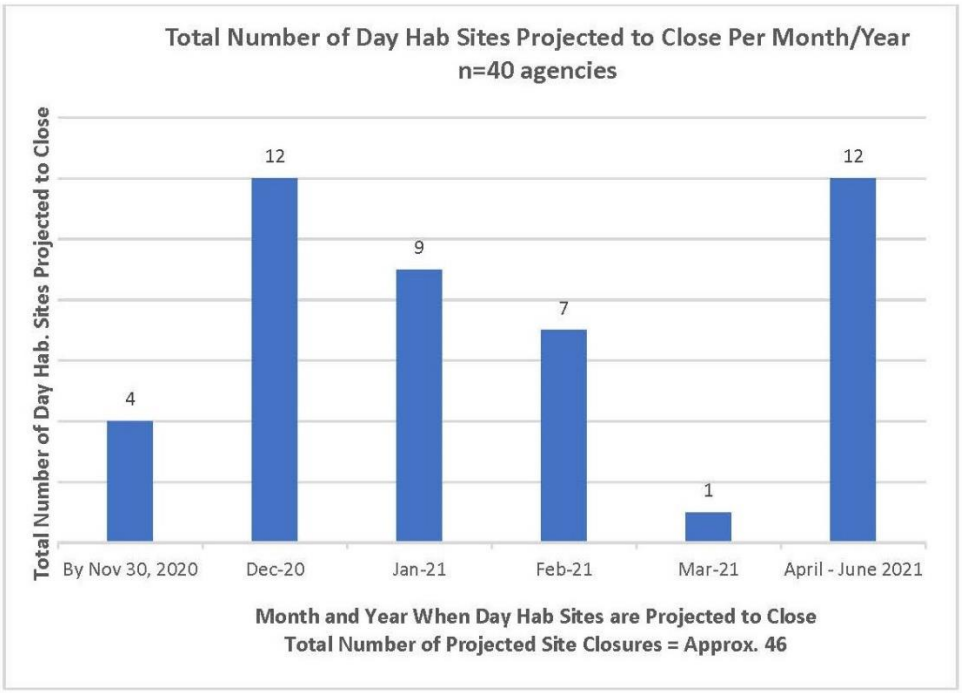
Providers were asked to respond to the survey based on the enhancement schedule remaining on course to end on November 30, 2020. Nine site closures occurred during April to September 2020. Those sites are outlined by DDS region in the following chart.



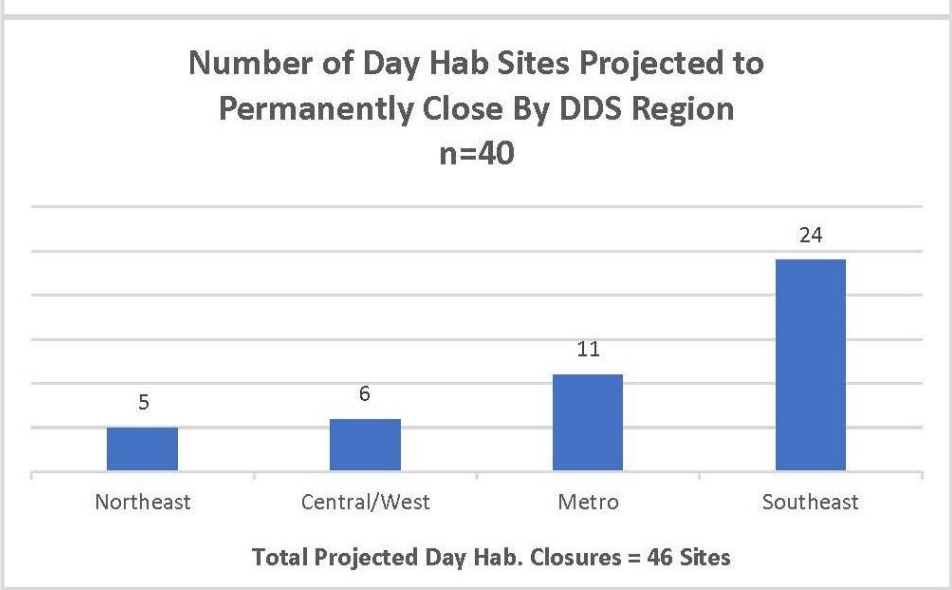
Providers noted that an additional 46 sites were projected to close over the course of fiscal year 2021 impacting approximately 3,061 individuals. An approximation is used given a slight variation in responses. The number of individuals impacted (i.e. gap in service) per month is represented in the chart below.



If a rate enhancement does not extend beyond November 30, half of the site closures are projected to occur in December 2020 and then again in April through June 2021.



Site closures were also extracted by DDS region. Most of the closures are expected to occur in the Southeast and Metro regions as displayed in the following chart.[1]



Caregiver Capacity

For individuals who (A) have not returned to the Day Habilitation program (either on site or remotely) and (B) are living at home with family members, providers were asked to report if caregivers had expressed interest in residential placement for their family member.

Providers reported that 50 families sought residential placements with a total number of eight individuals securing a group home placement due to caregiver stress related to not receiving Day Habilitation services during the pandemic.

Providers also reported a total of **877 individuals who have not received any** in person or remote Day Habilitation service since programs closed in March 2020.

Impact of Day Habilitation Members Not Receiving Services

Member Health is on the Decline

To understand the impact of no service on members, their families, and the state, it is important to review the profile of individuals served in Day Habilitation. The program serves some of the most vulnerable members in the community-based system. Many members have come from institutional settings, such as nursing homes and state schools, because of class action lawsuits. The majority of those served in the program have complex emotional, behavioral, and medical needs that require on-going supports and services to achieve positive health outcomes. As a result, most members have been rated in the "high" severity profile range according to the Day Habilitation Recipient Profile Tool. Members served in the program tend to have medically complex comorbid or co-occurring conditions, such as seizure disorders, neuromuscular disorders requiring feeding tubes, diabetes, congenital and acquired heart conditions,

[1] Site location is based on the provider agency's administrative building address

obesity, respiratory disorders, physical and sensory disabilities, mobility challenges, speech and language disorders, mental health conditions, and behavioral challenges.

The Day Habilitation model is an integrated community-based program that leads to improved health outcomes. The program's model is framed to address the members' following social determinants of health:

- Education is provided to maintain and develop new skills in the eight service need areas, such as affective development and sensorimotor development.
- Social environments allow socializing with peers, creating supportive relationships with staff, and developing communication skills.
- Physical environment is enriching and structured to promote emotional well-being and positive behavioral supports and the development of healthy behaviors, such as exercise and nutrition.
- Physical health services are provided by nurses that includes health and well-being oversight, medication management, promotion of routine medical care, consultation with physicians, as well as providing therapeutic activities, such as range of motion (ROM) and stretching.
- Clinical service access to and health and well-being oversight by speech language pathologists and occupational, physical, and behavior therapists.

This program is crucial to the State, families, and residential providers because members are supported by the Day Habilitation nursing staff to monitor health conditions, manage medications, and adhere to preventive healthcare protocols, and, when necessary, consult with the doctors of persons served.

If programs continue to close and the safety net of these providers is dismantled, the health and emotional outcomes of members will continue to decline in the following way, potentially resulting in increased usage of emergency services, medical hospitalizations, admissions to nursing facilities and/or new residential group home placements:

- Increase in significant weight gain
- Increase in skin breakdown and infections
- Increase in confusion, memory loss, orientation today/time/schedules/routines
- Increase in anxiety, especially in social environments, and concern about routine
- Increase in behavior and mental health related issues, such as aggression, depression, yelling, and unrest
- Decrease in range of motion, such as contractures, inability to grasp, and loss of muscle tone
- Decrease in ability to self-ambulate, distance in ambulation, and ability to transfer
- Decrease in communication skills
- Decrease in ability to complete tasks independently
- Increase in lethargy, sleeping during day, difficulty sleeping at night

Both ADDP and the Massachusetts Day Habilitation Coalition have collected real-life stories of members who have remained at home without services since programs first closed in March 2020. Witnessing decline on the sidelines is heartbreaking. The downward impact to individuals' physical and emotional health leaves one questioning how much longer these members and their families can go before they reach a breaking point and require additional interventions or increased supports to help climb back to their pre-COVID baseline of health.

Two themes have been extracted from the stories collected: physical and emotional decline. Each bullet below represents a member served in which some have returned to the physical site location once day programs re-opened.

Physical Decline

- Increase in lower leg contractures due to the lack of range of motion/repositioning program that he would normally receive at the program.
- Increase in upper and lower extremity contractures due to lack of daily range of motion/gross motor/repositioning program while out of the program. Lives with mom who works, so she pieces together home coverage of her son.
- Decrease in ability to walk. When she returned to the program, she could barely walk from her seat to the bathroom in the program room without getting winded and complaining about knee pain. Pre-COVID, she was able to walk 150 feet twice a day without an issue.
- Increase tightness in upper or lower body. At home, he was unable to use a stander (medical apparatus used to place person in a vertical position), which is provided in the program. Physical and occupational therapy goals were not completed at home during the mandated closure.
- Decrease in ambulation tolerance, balance, and overall endurance. He is exhibiting newly developed tremors in in a left hand and shoulder. He was unable to do any ambulating (for various reasons, such as the layout of apartment and trouble putting on brace) during his time at home when the program was closed. Upon returning, only two times/week, he fell in the restroom. The distance he can walk is only half of his ability pre-COVID.
- Increase in skin break down. The program is normally on top of this issue and usually follows up with the residential group house and doctor for solutions. Without Day Hab. program monitoring, this issue has gone unresolved.
- Increase in smoking due to stress, which has led to smoker's cough. Her diabetes has gone out of control due to stress eating. Her caregiver is an essential worker who had to continue working, so the member was left with other family to provide care.

Emotional Decline

- Regression in behavior. He returned to behaviors, from over a decade ago, that he has not exhibited in years, such as fecal smearing, verbal outbursts, and bolting. He has engaged in very serious self-injurious behaviors while at home. He refuses to sleep and is now supported in a new (never needed before) staffing ratio of 1:1. He has no access to his therapist in person and is nonresponsive to telehealth supports.
- Emotional deregulation. This individual has severe obsessive-compulsive disorder. While home when programs were closed, his behaviors escalated to the point where his housemates wanted him to move out. His constant yelling from the time he woke up until he fell asleep was very hard for everyone to tolerate. He was taken to doctors and assessed by the behavioral team and was given a PRN (as needed) for agitation with limited effectiveness. Once he returned to the program and his routine, his behaviors decreased during the day. He was able to enjoy preferred activities again. Remote programming was not successful for this individual.
- Decrease in engagement with others. This person is much less communicative with others. He used to always be upbeat and talkative.
- Increase in negative behaviors since being at home. She is noncompliant and destructive. Family is in distress. She is unable to return due to her need for 1:1 staff to client ratio. She is not

compliant with transitions, has poor hand hygiene, and unable to stay in one location, wear a mask, and adhere to social distancing.

Even though these are stories about 11 members who lost the Day Habilitation service during the pandemic, these examples are not unusual and have been observed countless times in other individuals who have lost this service. It also demonstrates that regardless of the members' living situation, providers are witnessing unusual decline proving that Day Habilitation is an on-going support service that is vital.

Impact on Caregivers / Families and Residential Providers

The Day Habilitation model delivers integrated community services in an efficient and effective manner. When Day Habilitation programs were mandated to close in March, families/caregivers and community-based residential providers felt the impact. Caregivers have reported isolation, abandonment, fatigue, and the inability to manage increases in their family members' physical and behavior support needs. Their ability to cope for members at home has dwindled over time even once programs re-opened.

If there is another widespread day program closure or sites need to close due to financial reasons or an increase in positive cases, residential providers are not equipped to cover the shortfall associated with members losing their Day Habilitation service. Residential providers are currently experiencing staffing shortages, limited qualified applicants, and minimal or no nursing staff. Existing group home direct care staff are not qualified because they lack training on how to provide indirect therapeutic activities and procedures to maintain the physical well-being of Day Habilitation members. These providers also do not have oversight in place for the therapeutic interventions.

Other community healthcare supports, such as the PCA program, are not modeled to provide ongoing supports for the complex medical needs of the people served within Day Habilitation programs for an extended period. Access to these community services are also time limited. These programs do not have oversight in place for the therapeutic interventions nor are staff trained in providing indirect therapeutic activities and procedures to maintain the physical well-being of members. Additionally, PCA services require the family to arrange for, hire, and manage the PCA staff in the provision of services. Especially during the pandemic, this would be extremely burdensome to piece together care and services for their family members. Without the safety net of the Day Habilitation programs, this would leave families having to manage on their own when, in some cases, this is not possible due to the caregiver's need to work or their own health conditions.

If the additional 46 Day Habilitation sites that are projected to permanently close during fiscal year 2021 move forward with their closure plans, the detrimental impact to families/caregivers and residential providers will be further compounded.

Service System Stability

To serve members during and post COVID-19, it is extremely important for MassHealth to clearly communicate its' intent relative to the safety net and the Day Habilitation program in particular. Given the historic financial losses of Day Habilitation programs that are further compounded by COVID-19, providers are in dire need of information to evaluate the viability of providing this service going forward. Some of ADDP's long-standing members who primarily provide day services are now in the position of working with their Boards to determine if their organizations can remain in business given the current plans as communicated by MassHealth. Other ADDP members are operating at huge deficits and working with their Boards to determine if these services will continue to be provided as part of their service array.

Given the expected longevity of the pandemic, the development of the vaccine, its rationing and dispensing priorities and COVID's impact on the economy, we understand the need to re-design the Day Services system. However, system re-design is a major undertaking that will require the concerted efforts of the professionals with the knowledge, experience, and expertise to be successful. As we saw with the transition from sheltered workshops to community-based day and employment services, system re-design can take as long as three to four years to accomplish which was a far easier reconfiguration of the system than what is likely needed now. This means the existing system has to survive or the professionals needed to bring it through a conversion process will be lost forever to other sectors. As such, we are requesting that rate enhancements reflective of the governmentally imposed decreases in utilization capacity be continued.

As positive COVID rates continue to increase, there is an increased likelihood of a shut down. If the State mandates another statewide shut down this fiscal year, we are additionally requesting that retainer payments for Day Habilitation programs be provided. Without retainer payments, the provider network will shrink causing an additional gap in services for many members. In addition, providers will face the following challenges:

- Agencies will be unable to make lease and mortgage payments resulting in not enough program sites to support the service demand post COVID. It is anticipated that if a site closes, it will remain closed until a vaccine is widely available.
- Providers will be forced to lay-off more staff. Most agencies are self-insured for unemployment, so providers cannot afford furloughed staff salaries and unemployment. Agencies cannot afford to retain leadership staff or the cost of retaining staff for remote/virtual programming when they have enormous staffing costs due to unemployment.
- The loss of staff and physical site or program locations will mean a reduced capacity in the system to serve members in a federal entitlement Medicaid program when programs reopen. A closure will lead to members with the highest needs going without service that cannot be found elsewhere in the adult service system.
- National statistics show that in the human services sector, the non-profit field's return to work/rehiring is about 1% a month. A shut down will see this number shoot upwards again and the re-hiring process will be much more difficult due to the instability of employment in the system.
- Providers, if they survive the closure, will need at least six months to plan for reopening.

It would be beneficial for agencies to know now if there is a retainer backup plan, so that they can have constructive discussions with their banks, landlords, and insurance companies. The possibility that retainer payments may be re-established will give security to providers during these negotiations.

We appreciate the opportunity to share our thoughts with you about the Day Habilitation service system. We look forward to continuing to work with MassHealth as we plan together to re-design the system in consideration of the best interests of the individuals that we mutually serve. **In the interim, it is critical that Day Habilitation is funded at a level to preserve the service system and to avoid adverse impact to the health care system while meeting the medical and therapeutic needs of individuals served.**