



# Summary: Family Survey, Interviews and Focus Groups

Prepared for Massachusetts Department of Developmental Services, July 2021

## Introduction

The Massachusetts Department of Developmental Service (DDS) in collaboration with the Institute for Community Inclusion at the University of Massachusetts Boston conducted forums and surveys to solicit information from community-based day support and employment providers, family members, and people served by DDS. The purpose of these activities was to learn about the impact of the COVID-19 pandemic and implications for future approaches to day and employment services.

We distributed a survey to family members to learn about their experiences and to get their input about future approaches to day and employment services. We shared this survey through providers, social media, and through partners, such as The Arc of Massachusetts and the Association of Developmental Disabilities Providers. In addition, we held two small group meetings and several individual interviews with family members to get input from a more diverse group of families. This report summarizes the input we received from family members.

The family survey, interviews, and focus groups were conducted from March-May 2021. At this time, day and employment services had reopened, but most programs were operating at reduced capacity due to COVID-19-related safety measures for program sites and transportation. Additionally, most providers were experiencing staffing shortages that limited the number of people their program could support. Only 55% of the respondents had family members who had returned to in-person services at the time of this survey.

## Focus groups and interviews

Two focus groups and 21 individual interviews were conducted. While the participants in the interviews and focus groups were more diverse than the survey respondents, the key themes were similar. Family members were appreciative of the support they received from their family member's provider agency. Compared to the families surveyed, more families who participated in the focus groups and interviews received additional supports, such as supplies of masks, cleaning supplies, iPads, and food.

Some of those interviewed reported challenges with virtual services while others found that virtual services contributed greatly to their family member's well-being. Some were eager to have their family member return to day and/or employment services, while others had reservations, primarily due to health concerns. Several families expressed interest in increasing community engagement. Like the survey respondents, some family members expressed interest in continuing with virtual services for part of their family member's schedule while others were eager to return to in-person services. Some expressed a desire for in-home services.

Three themes that emerged were the needs of older caregivers, the needs of members of the Deaf community, and the needs of people with communication barriers. One focus group included several siblings. They noted that technology presented a challenge for their parents. The siblings' increased caregiving responsibilities had become more challenging as they faced additional demands to support both their family member with a disability and their parents learning new technology. Additionally, interviews highlighted the importance of addressing the needs of people who are Deaf and people who have barriers to communication. Some family members reported that the transition was easier for their Deaf family member because they were accustomed to FaceTime and other virtual communication tools. Family members of people with complex communication needs required alternative approaches to engage with virtual services.



This report was prepared by the Institute for Community Inclusion at the University of Massachusetts Boston, and funded by the Massachusetts Department of Developmental Services (DDS).

[www.EmploymentFirstMA.org](http://www.EmploymentFirstMA.org)



## Survey results

The majority of the 742 family survey respondents were parents of persons served by DDS. Eighty percent of the respondents identified as female, and 51% were age 61 or older. Ninety percent identified as white, and almost all respondents indicated that English was their primary language.

The average age of the respondents' family member was 36, and the majority (58%) reported their family member lived with them in their family home. Twenty-seven percent reported that their family member lived in a group home.

The survey asked respondents to identify the day and/or employment services received by their family member prior to the start of the COVID-19 pandemic. Respondents had the option to select multiple services.

Service	%
Community-based day support	53%
Day Habilitation	25%
Individual supported employment	24%
Group supported employment	16%
Not sure	13%
Self-direction	6%

The survey asked respondents if they had changed the way they received day and/or employment support by moving from services offered by a provider to self-direction. While 25% of respondents reported that they had moved to self-direction, 23% of respondents indicated that they did not know. We recommend using caution in interpreting these results.

As previously noted, only 55% of survey respondents reported that their family member had returned to in-person services at the time of this survey. The majority of these respondents reported that their family member was participating in a site-based service.

What type of service is your family member participating in? (Check all that apply)	%
Program center or site-based	76%
Individual supported employment	20%
Small groups spending time in the community	13%
Group supported employment	11%
Other	8%

Families reported a variety of reasons for not returning to in-person services.

Why hasn't your family member returned to in person services? (Check all that apply)	%
Continued concerns about health and safety at this time	52%
The program capacity was limited	35%
Other	24%
Transportation was not available	17%
Residential program restrictions	12%

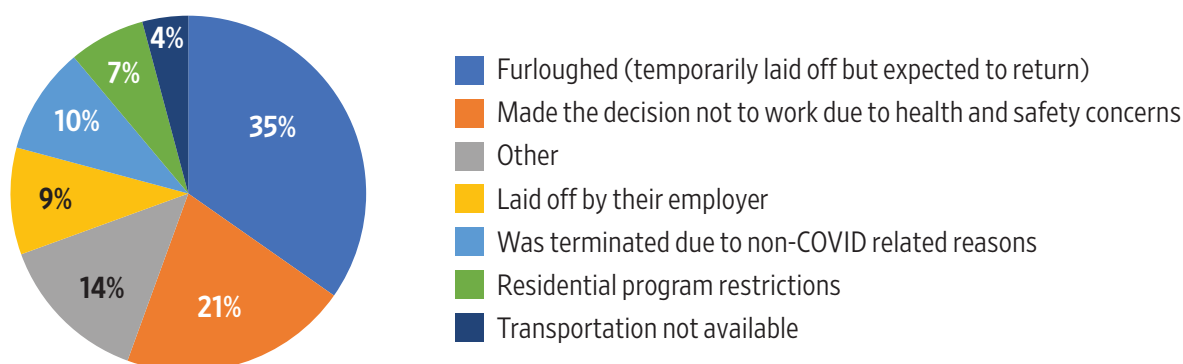
Those who responded "other" noted that the program site or job was closed (24%), identified concerns about their family member's ability to wear a mask and/or socially distance as well as other safety concerns (23%), reported lack of communication from the program (5%), and dissatisfaction with the available service options (4%) as reasons their family member had not returned to in-person services. Two respondents noted that the group home was providing day services.

## Individual Supported Employment

Ninety percent of the respondents who indicated that their family member was engaged in individual supported employment services prior to the pandemic indicated that their family member was employed in an individual job in March 2020. Only 50% were employed at the time of the survey.

Furlough or temporary layoff was the most frequent reason that individuals were no longer working.

### Individual employment: why no longer employed?



The survey asked respondents about their family member's experience with remote supports on the job. Forty-one percent of those working received some support on the job remotely. Seventy-six percent of respondents felt that these supports met their family member's needs.

The survey also asked about their family member's experience with other virtual services to support them on a job, support development of employment skills, and/or help them to sustain a focus on employment. Fifty-four percent of respondents reported that their family member participated in these services. They noted that these services helped their family member maintain job-related awareness and skills and offered practical knowledge and reinforcement of safety protocols for COVID-19.

Those who were receiving individual employment supports who did not use virtual services reported a variety of reasons.

What were some of the reasons your family did not use virtual services? (Check all that apply)	%
While we have the technology, engaging in services provided through a computer or tablet was challenging due to my family member's learning style, attention, or cognitive abilities	25%
Virtual services were not offered to my family member	24%
Virtual services were not needed	24%
My family member did not want to participate in virtual services	23%
My family member continued to receive support in-person	10%
My family member chose not to participate in services until they are comfortable returning to work	10%
My family member had trouble using the technology and needed more support than we could provide	9%
Other	6%

Comments from respondents indicate that the quality of virtual services varied greatly by provider. One respondent noted:

*"The services provided by his job support program were excellent in that they addressed social needs, and education about the pandemic, mental health, self-actualization needs while in lockdown, also some general knowledge. They provided amusement and fun too."*

Others reported that technology was poor and difficult to hear and that the offerings, while initially good, changed when the staff member left and were no longer of interest to their family member.

## Group employment

Eighty-four percent of those who indicated that their family member received group employment services prior to the COVID-19 pandemic reported that their family member was employed in March 2020, and 30% reported that their family member was working in group employment at the time of the survey.

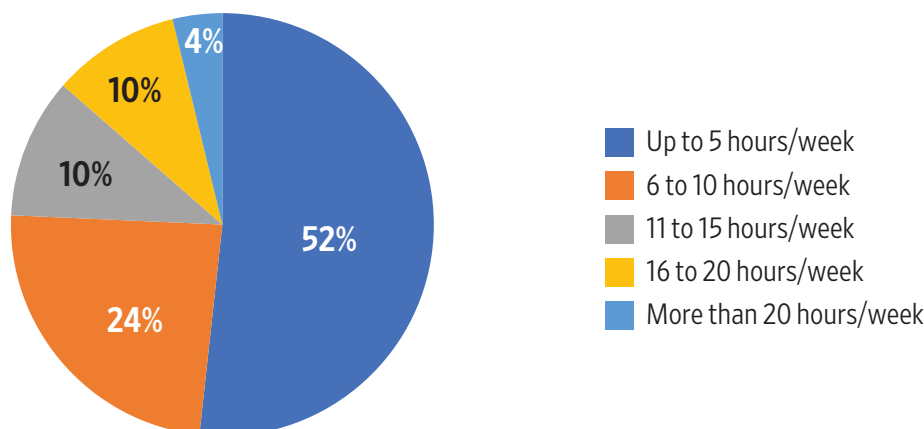
Why are they no longer employed?	%
The job is not currently available	53%
Other	19%
Made the decision not to work due to health and safety concerns	11%
Residential program restrictions	8%
Transportation not available	8%

## Virtual services

Those who reported that they received community-based day supports and/or group employment services were asked about their experiences with virtual services. Seventy-five percent of these respondents reported that their family member participated in virtual services, 21% indicated they did not participate in virtual services, and 5% were unsure.

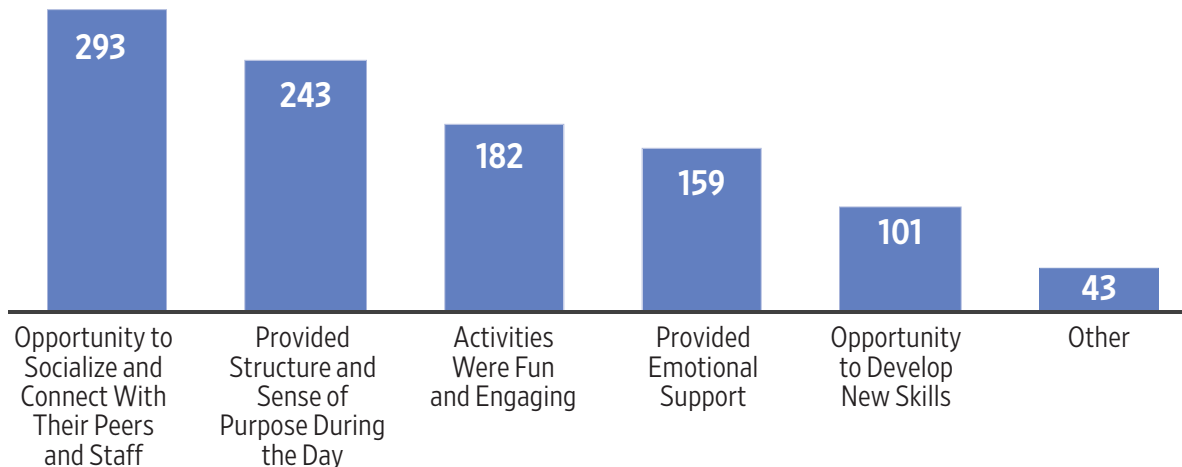
Those who indicated that their family member engaged in virtual services were asked about the number of hours per week their family member participated in these services. More than half (52%) participated in virtual services only up to 5 hours per week.

**On average, how many hours per week has your family member participated in these services?**



We asked those whose family member participated in virtual services what they felt was most beneficial to their family member.

**What do you think was most beneficial to your family member about participating in these virtual services? (count)**



One parent noted that that they were invited to join in on Zoom, which made both the parent and their family member feel more included. Other respondents noted that it gave their family member a sense of belonging. Others noted that the curriculum was valuable. Respondents also mentioned music and fitness classes as positive experiences.

Of the 43 other responses, the majority (56%) indicated that virtual services were not helpful or were stressful. Several respondents mentioned that their family member's need for support to participate limited the opportunity to engage in virtual services.

Those who reported that their family member did not participate in virtual services were asked to identify some of the reasons or barriers to using virtual services.

What were some of the reasons or barriers that made it difficult to use these virtual service approaches? (Check all that apply).	Count
My family member didn't want to participate in virtual services	35%
While we have the technology, engaging in services provided through a computer or tablet was challenging due to my family member's learning style, attention, or cognitive abilities	30%
My family member had trouble using the technology and needed more support than we could provide	14%
Other	9%
Virtual services were not offered to my family member	5%
We did not have a phone, tablet, or computer that my family member could use	5%
We don't have internet access, or it didn't work well	< 1%

Many respondents noted in the comments that virtual services did not work for their family member for reasons such as overstimulation, stress, unreliable or inconsistent services, and family member could not effectively engage with the service modality (23%). Some respondents noted that their family member needed support to participate, and they were not able to provide this due to other responsibilities or that the group home was not able to support engagement (3%).

## Additional services

Many providers, particularly those who operate Family Support Centers, provided a range of additional services to families. Eighteen percent of survey respondents reported that they received additional supports from a provider or Family Support Center. These included in-home supports, a computer or tablet, assistance with food, help with internet access, and a range of other supports.

## Considerations for future services

To help DDS plan for future services, we asked all respondents what options they would like to see as part of their family member's services if DDS were to have the opportunity to make changes in current approaches.

Should DDS have the opportunity to make changes in current approaches to services, what options would you like to see as part of your family member's services?	Count
Services provided in small groups in the community	333
Virtual services as part of my family member's weekly schedule	168
A more flexible program schedule	159
Transportation options that don't require my family member to go to the center first before going to work or into the community	131
Other	119
Remote support to facilitate independence at work or in the community	110

Out of 119 “other” responses, the most common comment (25%) expressed a desire to return to supports as they were before the pandemic. Ten percent of respondents mentioned more access to community activities. Transportation was a common concern, representing 7% of the responses, with most expressing a desire to return to regular transportation to services, but some suggesting more flexibility, including direct transportation to a community job and the use of alternatives such as Uber at a flat cost.

Additional requests included support for finding a community job and more flexibility in services, including a longer day and weekend supports. Additionally, there were multiple comments about services that were not at the proper level for their family member. In some cases, respondents noted that their family member needs greater stimulation and challenge, while others expressed concern that their family member needs a more appropriate level of support that matches their level of functioning, including services such as occupational therapy (OT) and physical therapy (PT). Taken together, these speak to the need for greater individualization of services and supports. There were several respondents who expressed concern that DDS might be planning to close community-based day support programs.

The survey also asked respondents what is most important to them when considering day and/or employment support for their family member.

What is most important to you when considering day and/or employment supports for your family member?	Count
The opportunity to develop relationships and friendships	407
Structure and a predictable schedule	406
An approach to services that is based on my family member’s interests and goals	326
The opportunity to develop new skills	280
Being engaged in the local community	214
Assistance to obtain paid employment	140
A flexible schedule	44
Other	27

Some respondents commented that they just want their family member to be safe, happy, and engaged. Several respondents identified the lack of speech therapy, OT, PT, and behavioral supports as a gap. Respondents also noted the importance of having choices and opportunities to engage in volunteer work, employment, and other activities that align with their family member’s interests as well as the importance of having opportunities to contribute to society.

## Additional suggestions and comments

The survey provided an opportunity for respondents to provide additional suggestions about how DDS might provide services in the future. There were over 400 responses to this question, and they have been organized by key themes:

- Virtual services
- Community engagement and community-based day support services
- Employment
- Transportation
- The COVID-19 pandemic response
- Return to in-person services
- Suggestions for future services and support

### Virtual services

Virtual services generated the largest number of comments. Feedback related to virtual services varied greatly. Some families noted that skill development opportunities continued virtually and provided an opportunity for their family member to stay engaged. Respondents cited group Zoom calls as beneficial to their family member’s mental health and provided opportunities for socialization during a very isolating



time. Some respondents described Zoom sessions as interesting and enjoyable, while others noted that more variety and structure was needed. In some cases, individuals learned to use technology in a way that their family would never have expected.

Feedback indicated that some with autism spectrum disorders (ASD) found it easier to engage in remote services. Some respondents indicated that the person they support participated in services they otherwise would have resisted should they have been offered in person.

*“It opened up a whole new world for her!”*

Some families noted that virtual services were of great benefit to their family member and expressed a desire for them to continue. Respondents noted that the ability to engage from home lessened the number of transitions their family member had to make, decreased fatigue caused by transportation and navigating the center, and in some cases, resulted in overall improved health. Some suggested that their family member would benefit from a schedule that allowed for some in-person services and some virtual services. Others hoped that virtual services might be an option should their family member not be able to attend a program due to health issues or inclement weather. One family member noted the risks of isolation that come with virtual service delivery.

*“There is an inherent conflict between virtual service delivery and what I would consider a potential for further isolation inherent in expanded use of technology. There needs to be a careful balance between these two things. It is important to maintain a live connection for social networking and skills building.”*

Other families noted that their family member did not engage in virtual group services. As noted in the survey responses, the reasons varied. Some respondents reported that their family member was not able to navigate the technology while others indicated that it just was not a format that worked for their family member. Others reported that their family member required 1:1 support to engage in group activities virtually. In some cases, they noted that virtual services were more effective when a staff member engaged on a 1:1 basis virtually. Several respondents noted that they had difficulty acquiring an iPad or similar device while others specifically commented on how much their provider did to get them a device and help their family member learn to use it.

## Community engagement and the future of community-based day support services

Consistent with the survey responses, family members identified engagement in the community as a priority.

*“This year confirmed how important community participation is, like going to the gym, volunteering, and recreational opportunities with friends.”*

Respondents noted that volunteer opportunities had been important to the person they support, and they were eager for this to start again. Respondents noted that these opportunities have been important for skill development and a pathway to employment. Many respondents also expressed frustration that, with the good weather, in-person services were not taking advantage of opportunities to get outdoors and exercise.

Going forward, there continues to be a desire for community access and increased focus on interests and skills. Family members suggested learning activities, varied experiences, and evaluating and redesigning opportunities quarterly.

*“CBDS [Community-based day supports] needs to have greater community access that is meaningful, educational, and geared towards vocational opportunities; it has felt more like field trips into the community with little true purpose”.*

Many respondents noted the importance of engaging people in activities and experiences that are interesting and meaningful to them as part of community-based day supports. They noted that many things are too repetitive for those who have been attending programs for a long time. Some family members suggested that programs should apply the same creativity they applied to Zoom offerings to in-person services.

## Employment

Many respondents were eager to see their family member return to work. They noted the importance of the opportunity work provides to earn money, develop social skills, develop confidence, structure the day, and make a meaningful contribution. Many were unclear if and when their family member might return to work, while others indicated that a return to work was imminent. Some respondents suggested that those who were no longer working due to the pandemic will need more support to build confidence and return to employment.

Some respondents noted that providers need to offer more opportunities for employment, specifically referencing the need for renewed emphasis on helping their family member find employment and providing support as needed to promote success on the job. One parent stated that the employment services previously offered at their daughter's agency seem to be gone. There was acknowledgement that the workforce crisis is a challenge for providers and that employment staff need more training to be effective.

Several respondents noted that would like to see their family member work part-time with supports and have options for a day program on days that they are not working. Others noted the importance of a job, the option to go directly to work each day rather than meeting a job coach at the center, and the option to get access to employment services without having to attend a day program. Respondents also noted a need for career advancement support.

Respondents noted that there was a need for better communication with families about employment opportunities. One family noted that their daughter asks to get a part-time job at her Individual Support Plan (ISP) meeting every year, yet she is not receiving any assistance obtaining employment.

Similarly, others noted that more paid work opportunities are needed.

*"We were extremely happy when he was chosen for individual employment support in the community – he is SO much happier, less frustrated, and feels productive and engaged – thank you!"*

Several respondents spoke highly of the job coach support their family member received. Other family members were concerned about the lack of support for those who were working and the perception that providers are only able to support job seekers on jobs they got with support from the provider.

*"He received no job coaching for six months and then problems arose at work. There was no consistency with his employment support schedule. Even when he was considering quitting due to problems."*

Another respondent noted that the person they support has been in "training" since pre-COVID and is yet to get paid. Others cited the lack of job coaching services needed for their family members to be employed.

*"...desperate need for more job coaching to get our family members working and part of the community."*

Three respondents stated that DDS should reconsider options for sheltered employment at subminimum wage. They each noted that their family member is unable to meet the productivity requirements in supported employment but wants to earn a paycheck.

## Transportation

Respondents identified transportation as a barrier to accessing services and employment. Most respondents spoke to the lack of transportation services as community-based day supports and group and supported employment services reopened. There was an added burden on families who were, in some cases, driving their family members to work or a program site. Others noted that better transportation options are needed so that their family members do not spend so much time on vans.

*"It was broken before COVID. My sister was on a van with 8-10 people, she had no choice. Her day program was 10 minutes from where she lived but was on the van over an hour due to the route."*



Another respondent observed that her family member who uses a power wheelchair rarely has had opportunities to be in the community rather than the center and felt that lack of accessible transportation was a barrier.

Others noted that changes in public transportation routes in some communities eliminated opportunities for independent travel.

Going directly to work from home without stopping at the center was one positive change that some experienced because of COVID-19. This had the added benefit of fewer transitions each day.

## In-person services

While many family members were eager to have their family member return to in-person services, some expressed concern that their family members had returned to a building with nothing to do all day. Some respondents noted a lack of opportunity to engage in the community, observing that many things had reopened to the public, but community-based day support programs were not accessing these opportunities. Some also expressed concern about hybrid approaches where those who returned were still engaged via technology to include those participating remotely.

With the return to in-person services for some, respondents noted that it was beneficial to have smaller groups and fewer staff to interact with daily. Others noted a preference for community-based services rather than congregate settings.

COVID-19-related mitigation was a barrier for some to return to in-person services, including the ability to wear a mask.

## Responding to the impact of the COVID-19 pandemic

At the time of this survey, there were widely divergent opinions about the response of DDS and providers to the pandemic and the re-opening of in-person services. Several respondents noted that DDS and providers need to develop contingency plans to more effectively meet the needs of persons served by DDS should a similar crisis occur in the future. Multiple respondents expressed frustration with the lack of communication they received from DDS and/or their provider. Likewise, multiple respondents noted difficulty communicating with the service coordinator. Some respondents also expressed frustration with the pace of re-opening and the pandemic-related mitigation measures, including social distancing and mask requirements. Many desired a return to a normal life with pre-pandemic services and supports.

*“Get it back to where it was before COVID-19. Enough. Five days a week and out in the community. Vaccines are available. Let’s get back to normal.”*

*“..... people with disabilities are not treated the same as typical peers. They have far more restrictions and modifications than others their age in college or high school.”*

Comments by respondents reflected highly variable experiences both across providers and even within a given provider.

*“There needs to be a certain expectation of services offered throughout all agencies. I have heard that some programs offered a rare opportunity for virtual events. And some offered multiple things per week. There was little consistency in supports, services, and communication. Expectations were not in place or were not followed.”*

Several respondents whose family members lived in residential settings expressed concern about staffing and the inability of their family members to engage in remote services.

At the same time, many respondents expressed appreciation for the efforts DDS made to support those individuals served. Particularly, many respondents expressed appreciation for providers who pivoted quickly to providing services virtually, facilitated access to iPads and other devices, worked with people they support and family members to help them learn to use technology, delivered program materials to homes to help individuals engage in services and virtual activities, and provided support virtually or in person to those working in essential jobs.

*"We are very grateful to [the provider] for their dedicated and creative way of keeping our daughter engaged throughout this pandemic. It was a lifesaver."*

*"Current day program at [provider] has been fantastic in providing appropriate support, creatively adjusting for safety and participant needs. They think outside the box and keep services fresh, exciting, and energetic, engaging and maximizing [participant's] day."*

*"For our son, we believe [provider] provided an excellent, diverse, and routine program for him while home. He became totally independent in participating in online activities and loved it. I loved it too because I got a better understanding of what the program and classes were all about."*

*"His program was exemplary with staff and supports rising up to meet my son's needs in every way possible".*

Finally, multiple respondents noted the tremendous impact on parents when suddenly their family members were at home full-time. The inability to get personal care attendant (PCA) or other in-home supports exacerbated this challenge, particularly for some older parents. Several parents noted that they lost their jobs because of the level of caregiving responsibility they needed to assume. Others suggested that when programs closed MassHealth, DDS should have provided increased in-home support so that parents who were essential workers could avoid putting their employment at risk.

### Suggestions related to future services and supports

Survey respondents provided suggestions for how services and support might be restructured to better meet their needs and the needs of the person they support. In some cases, the options respondents suggested are already available, speaking to the need to better educate caregivers about options that might best meet the needs of their family member.

*"I am grateful for the virtual and in-person support provided during this difficult time. I am hopeful suitable part-time employment can be acquired eventually with DDS funded job coach services plus continuation of day program options on weekdays when not working. I think the evolution of virtual programming, consultations, and skill development adds a useful dimension to the DDS funded services that were available prior to March 2020."*

Most common was a desire for more flexible approaches to services. Some of the suggestions included:

- **Blend self-direction and day services.** Create flexible community-based day support schedules that better align the participant's schedule with preferred activities, including part-time schedules.
- **Offer service on Saturdays.** Consider providing opportunities for small groups to meet up/gather in community settings rather than the program.
- **Make virtual services a permanent part of the service array so they can be integrated into an individual's schedule/services in a way that makes sense for them.** Offer hybrid services that allow individuals to develop their schedules to include in-person services on some days and virtual services on others.
- **Increase focus on mental health.**
- **Create opportunities for families to create their own programs with financial support from DDS.**
- **Increase in home support.**

Additional comments addressed the needs of specific groups of people DDS serves. The need for more clinical support for individuals with severe autism was raised by multiple respondents.

*“DDS needs to address the lack of appropriate day services for adults with have severe forms of autism. The jump from intensive ABA program from 3-22 to the DDS adult day programs is extraordinary and was not successful for my child. 100% decline in self injurious behavior since her day program closed leads me to believe she was in the wrong program.... I would be willing to accept fewer hours with well-trained ABA staff... coordinating a self-directed program.....is a daunting task for a parent.”*

Others felt that existing programs don’t meet the needs of people who are DDS-eligible but do not have an intellectual disability. Some respondents noted that people who are aging need more choices. DDS must consider other approaches for those who need a retirement model, including connection with senior centers.

## Conclusion

Family members and caregivers illuminated strength, setbacks, service gaps, and expectations for future services from their experience receiving services during the COVID-19 pandemic. The perspectives of family members and caregivers, along with those of people served by DDS, DDS service coordinators, and community-based day support and employment providers will be important as the state moves forward in restoring and enhancing community-based day and employment supports in Massachusetts.



This report was prepared by the Institute for Community Inclusion at the University of Massachusetts Boston, and funded by the Massachusetts Department of Developmental Services (DDS).

