



Are you getting what you need? Are you connected? Survey Results of adults with disabilities and families of adults with disabilities during COVID-19 and Lessons Learned from the IPAD Technology Project

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Maine Developmental Disabilities Council

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Introduction

In April 2020, the Maine Developmental Disabilities Council worked with parent advocacy organizations to conduct a survey to assess how minor children with disabilities and their families were faring during the isolating period of COVID-19. One result of the survey was that 26% of parents had not been contacted by either their child's case manager or service provider. The Council conducted the following survey to assess if the same was true for adults with developmental disabilities and identify what services/information was being provided to them.

82 adults with disabilities or loved ones of adults with disabilities completed the survey. 27% of respondents were from Aroostook County. York (15%), Penobscot (13%), and Androscoggin (11%) were also well represented. The remaining respondents represented 9 other counties throughout the State of Maine.

62% of respondents utilize day programming, far more than any service other than case management. 35% utilize home supports in their or a family members home, 30% receive supports in a shared living program, 29% in a residential setting, and an additional 4% are typically served in residential settings but are currently in a family member's home. 5% of respondents only receive case management only. Of the remaining respondents, 7% receive no services and a few noted that they are on a waitlist.

Executive Summary/Impressions

Largely, respondents indicate that their case managers are communicating with them and, when possible, meeting their needs.

Aside from case management, the service most utilized is day programs. Most programs have adapted their delivery patterns to meet the requirements of social distancing, but this is not consistent across the State with some respondents having been offered no services at all. **42% of respondents, whether they are receiving modified programming or not indicate that their needs from day programming have not been met.**

Consumers who live in group homes have not fared as well, as 25% are at home, some by choice and some forced to by shuttered programs. 8% have not heard from their group home providers (presumably since moving to a family member's home).

Respondents answers indicate general satisfaction regarding quantity and quality of information from Case Managers and Service Providers but **79% of respondents stated that they do not get enough information directly from DHHS.**

Results

Case Management: 83% of respondents have heard from their case manager, although 5% noted that contact with the case manager has been only occasionally. 13% of respondents have not heard from the case manager. Of those who have heard from their case manager, 76% stated that their needs have been met while 14% responded that needs have either been partially met or their needs have not been met.

Day Program: 62% (n=52) of all respondents utilize day programs.

25% (n=13) stated that their day programs are completely closed. 12% were offered no services at all and 8% have not heard anything from their day program.

65% (n=34) are currently receiving modified services, most likely through remote/telehealth. Of those receiving modified services, 23% indicated that their needs are not being met.

Only 2% of respondents opted out of services due to COVID-19.

Home Supports: 35% (n=29) respondents receive home supports in their home or a family member's home. 52% of respondents continue to access usual services while 45% are receiving modified services. Very few indicated that their needs are not being met.

Shared Living: 30% (n=25) respondents receive shared living supports. Only 1 respondent stated that their service has been modified.

Residential: 29% (n=24) respondents live in a residential program. 58% of those who live in group homes are receiving typical services. The remainder have moved home. Of the 42% that have removed home, half state that their needs are met through a modified program.

To qualify, 75% of individuals who previously lived in a group home either continue to live in the group home or are experiencing modified services that are meeting their needs. The remaining 25% are not getting their needs met. 8% have heard nothing from their provider or have had not services offered. The others are accessing modified programming of some kind.

Why are you not getting usual services? 54% (n=44) of total respondents answered this question. The most frequent response was "I Don't Know." (32%), followed by the personal choice to withdraw from services (20%) and the belief that services were modified or withdrawn due to COVID-19 (18%). The remaining responses included No Access to Technology, Not Enough Staff, Only Offering Remote Services, and finally the Program Closed (1%).

Who do you get your information and how is it meeting your needs? Only 1 respondent replied that they have received no information at all and 1 respondent replied that they receive information from the news. The remaining respondents are represented in the chart below.

Source	% who receive information from source	Meets needs/Helpful	Do not receive enough information
Case Manager	76%	89%	11%
Service Provider	62%	63%	37%
DHHS	41%	21%	79%

Are there things you or your family need but can't get? 19 individuals identified the following needs. Because of the small numbers, it is difficult to identify trends.

Groceries	3
Protection from abusive family members	2
Don't Know	2
In home supports	2
PPE	2
Transportation	2
Assurance that service will re-open after covid	1
Information about residential testing	1
Life without stigma of disabilities	1
Need to leave the building	1
Safety Plan	1
Support while family works	1

Access to Technology

At the inception of the Covid19 public health emergency, the Maine Developmental Disabilities Council became concerned about the potential impact of social isolation on already vulnerable Mainers with developmental disabilities.

The Council identified a number of systemic issues related to the digital divide. In June 2019, the Pew Research Center reported that “The internet represents a fundamental shift in how Americans connect with one another, gather information and conduct their day-to-day lives.”

(<https://www.pewresearch.org/internet/fact-sheet/internet-broadband/>) The study further reports that 88% to 97% of Americans are connected. In 2018, the Bangor Daily News reported that 86.4% of Mainers have internet access, with Maine lagging behind the nation in broadband access.¹ The Council asked: **are people with developmental disabilities being able to access this critical community connection at even close to the same rate as everyone else?**

Maine participates in the National Core Indicator (NCI) project, in which approximately 400 individuals with DD who receive adult developmental services are interviewed annually about their quality of life. While the survey does not, as of the drafting of this report, ask about access to technology, it does ask about access to cell phones. While this likely includes smart phones, it may also include phones with limitations such as the old “flip” phone or a track phone. Regardless, although imperfect, this data provides another data-point to assess access to technology. The 18-19 responses of the NCI survey indicates that 56% of respondents owned a cell phone and 45% of respondents indicated that they *want*

¹ Valibra, Lori (August 10, 2018) Accessed at [Study: Maine Has Average Broadband Access for U.S., but Lags Behind the Rest of New England](https://www.govtech.com/network/Study-Maine-has-Average-Broadband-Access-for-U.S.-but-Lags-Behind-the-Rest-of-New-England) Retrieved from:

(<https://www.govtech.com/network/Study-Maine-has-Average-Broadband-Access-for-US-but-Lags-Behind-the-Rest-of-New-England.html>) May 26, 2020

a cell phone.² This data suggests that Maine adults with DD who receive adult waiver services are lagging significantly behind Maine's other citizens, let alone the nation's.

In March, the Council funded a pilot project to provide an opportunity for Mainers with developmental disabilities to increase their connection to family and friends, services, telehealth, and opportunities for self-advocacy through direct access to an iPad. Funding was limited to 148 devices. iPads were awarded statewide through an application process.

The application was available for only one week. Direct outreach regarding the program was a single email sent to 31 recipients. The Council received approximately 375 eligible applications from adults.

Given that the application process was open for a very limited time, only those who *wanted* an iPad were encouraged to apply, *already having access to wireless internet was required*, and the *only outreach was one email to 31 recipients* it is safe to posit that **the need is far greater than suspected.**

During the time of social distancing and COVID-19, where the need to connect virtually has redefined community, the Council is concerned that the digital divide for people with developmental disabilities. Certainly, this project has placed a spotlight on how current access to technology is not the same as people without disabilities. **The result of this inequity is that people with developmental disabilities will have less access to the community, as it is being redefined in our culture, and that will likely have consequences to people's quality of life during COVID-19 and otherwise.**

Assistive Technology: In the process of reviewing applications for iPads, the Council identified potential barriers in accessing assistive technology through MaineCare or other disability related benefits. There were at least 50 individuals who, based upon the (limited) information provided, it appeared would benefit from an assistive technology assessment and professional support to address disability related communication deficits. While there was limited information provided and relatively small numbers, it is notable that almost all were waiver recipients who ostensibly have access to assistive technology **and** whose case managers assisted them with the application, suggesting that there is likely a gap with some aspect of the process of using the AT benefit. Lack of the ability to communicate effectively significantly decreases health and wellbeing. Without the ability to communicate one cannot function in society, let alone advocate for ones needs. The Council hopes to work with the system in the future to ensure that people have access to the medically necessary tools that they need to communicate.

² National Core Indicator (2019) National Core Indicators® 2018-19 In-Person Survey (IPS) Report Retrieved from: https://www.nationalcoreindicators.org/upload/core-indicators/Rights_and_respect_508_IPS_18_19.pdf May 28, 2020