



How are you doing? Survey Results of families of children with disabilities during COVID-19

Distributed and Results Analyzed by:

Autism Society of Maine

Developmental Disabilities Council

Maine Parent Federation

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Introduction

Children often have difficulty with significant unexpected change in their daily lives. This difficulty is exacerbated by children with disabilities who often rely on families and additional staff support in schools or at home to successfully navigate their days and advance successfully through child development. COVID-19 has significantly changed the lives of almost every person in Maine. This survey was focused on collecting information about how families are fairing with disrupted school and home services. Themes are analyzed and general information was collected to assess how communication from these various settings are going. The survey was distributed through Facebook and email list serves by Maine Parent Federation and the Autism Society of Maine. The Maine Developmental Disabilities Council assisted in theme analysis. All three-organizations collaborated in the preparation of this report. There were 148 responses to the survey, though each respondent did not reply to every question.

Executive Summary/Impressions

For the most part families with children are doing okay as they focus on educating their children. The fear of regression has overtones in many of the responses although only 1/5 used the actual word. Many families are educating their children while trying to work and some are experiencing financial hardships. Close to 40% of children are struggling with homeschool and some are exhibiting challenging behavior. The most striking finding in this study is that 1 in 4 families are either not being communicated with or/and need additional communication from service providers and schools. 23% of families reported that they need more direct help from schools on how to deliver distant or remote learning to their children with disabilities. 26% of families have not heard anything at all from case managers or in-home service providers.

Results (148 Respondents)

Thematic Questions: Question 1: “What is the number one concern your family is facing at this time?” And similarly, /yet with a slightly different nuance **Question 5: “Are there things you or your family need, but can't get? What are they?”**

Interpretation of questions yielded extremely similar answers which is why thematic analysis combined the two datasets. Only 8% of respondents indicated that they had no concerns or needs other than preventing COVID-19. Below are the results of the theme analysis.

- **42% are Homeschooling**
 - 42% of all respondents (n=148) indicated that homeschooling was the most important thing on their mind.
 - **61% of those homeschooling noted that they were significantly concerned with homeschooling** and it was the most concerning issue in their lives.
 - **47% were worried about regression.**

- **39% are finding homeschooling especially difficult while they are working (either from home or as an essential worker)**
 - **23% specifically stated they needed additional guidance and strategies about how to teach their child at home.**
- **20% Regression** - 20% of all respondents specifically stated that they were concerned about their child regressing.
- **17% In-Home Supports** – 17% of all respondents stated that they needed individualized in home supports and couldn't get them even though that profession is deemed an essential service. A few of these respondents wanted in-home supports to help with education as they had section 28/65 services in schools. Most wanted in home supports in assistance of dealing with some type of challenging behavior.
- **11% Challenging Behavior** - 11% of respondents communicated their children were exhibiting challenging behavior such as property destruction or aggression.
- **10% Preventing the Loss of Social Skills** – 10% of respondents were very concerned that their child with Developmental Disabilities were losing the social skills that they had worked to gain.
- **8% Mental Health** – 8% of respondents stated that they are very concerned about either their personal mental health, their child(ren), or both.
- **7% Difficulty Accessing Technology** – 7% of respondents either did not have reliable access to the internet or do not have suitable computers.
- Less frequent themes (Under 10 responses)
 - 6% worry about finances
 - 5% have children in the middle of transitioning to adulthood
 - 5% indicated difficulty navigating this new routine
 - 4% were having difficulty accessing healthcare like prescriptions or time with medical practitioners.
 - 4% have not been able to get mental health or speech/occupational/physical therapy through telehealth
 - 4% are worried about their or their child's safety.
 - 3% need adult services
 - 3% need assistive technology such as therapy swings.
 - 3% are struggling to get enough groceries.
 - 3% have children in residential settings and they worry about being away from them.
 - 3% of families stated that they are unemployed.
 - 1% said they need respite.
 - 1% was in crisis.
 - 1% specifically stated they need case management.

Question 2: “If your child is in school or receiving CDS services have they reached out and contacted you?” **17% of respondents (n = 131) had not yet been contacted by CDS or school system.**

- 131 people responded to the question
 - 81% yes
 - 17% no
 - 9 schools from Cumberland County (2 were distinct special purpose programs)
 - 3 schools from York County
 - 2 schools from Androscoggin County
 - 1 school from Penobscot County
 - 1 school from CDS

Question 3 asked “If you or your child/adult is receiving services from either case manager, in home provider, waiver program have they reached out to you with information about services or any updates?” **1 in 4 people have not been contacted by their case manager or in-home supports provider.**

- 123 people responded to the question:
 - 74% Yes
 - 26% No

Note: Question 4 focused on whether respondents were able to access webinars related to specific agencies. The most common theme to this question was that individuals did not have time during their day to view webinars but many requested that the webinar publish an archived version or transcript that could be reviewed at a later time. All responses to this question are available upon request