

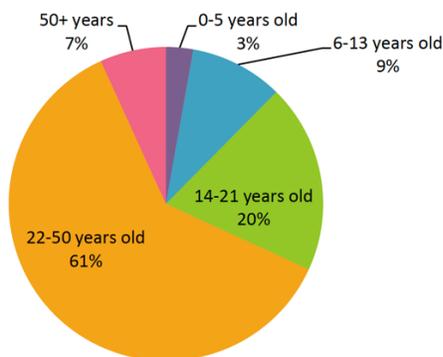
RI Family Caregivers COVID-19 Check-In Survey Summary

The RI Family Caregivers COVID-19 Check-In Survey was a collaborative effort by a coalition of advocacy partners to reach out to families of individuals with disabilities to see how they are doing during the COVID-19 crisis. Partners in this effort included RI Families Organized for Reform Change and Empowerment (RIFORCE), The Arc RI Family Advocacy Network, Paul V. Sherlock Center on Disabilities, Plan RI, RI Parent Information Network, RI Developmental Disabilities Council, Cross Disability Coalition. The purpose of this survey was to gather information from families that would inform ongoing advocacy discussions with State agencies to better meet the needs of individuals with disabilities and their families during this crisis.

The survey included 18 logic-based questions which allowed participants to answer a question and then, based on their answer, move onto a relevant next question. This was done for efficiency and ease of use and time for the family member responding to the survey. At the end of the survey participants were invited to share their name and contact information, and were asked if they would like one of the agency partners to contact them for support. The survey completion time was estimated as 10 minutes, was offered in both English and Spanish, and was administered from April 13, 2020 thru April 20, 2020.

In all, 254 family members responded to the survey, 230 took the survey in English and 24 took the survey in Spanish. Some individuals required support to participate in the survey which was provided by phone. Family members participating in the survey represented parents (82%), siblings (7%), grandparent (1%), and other family members (4%). Figure 1 illustrates the reported age ranges of the family member with a disability as reported by the participants.

Figure 1
Ages of Family Members



When asked to describe if they were doing “ok” during this crisis, 50% of families responded that were ok and have what they need. The remaining 50% reported that they do not have everything they need and of those 7% reported not being ok.

Overall, the majority of families reported getting their information from the Internet (86%), followed by the radio/TV (80%) and family and friends (56%). Others (16%) reported getting their information from sources including the Governor’s Daily Briefing, mailing lists, newspapers, list-services and co-workers. Ninety-six percent of participants reported that they were able to access the Internet and were using devices including computers (48%), laptops (64%), ipad/tables (57%) and chrome books (18%). Most notably was that 87% of participants reported using a smartphone to access the Internet. *It should be also noted, however, that this survey was primarily disseminated and administered through the Internet and therefore would not have captured those families who do not have Internet access.*

Of concern are the of families (14%) reporting they do not have Internet and/or a device to access the Internet. All of these families were Spanish-speaking. Of the Spanish-speaking respondents, where most surveys were completed by phone, a sizable group (44%) do not have Internet access at all. The majority of the Spanish-speaking respondents (91%) report getting their information through radio or TV, followed by family or friends (74%), while only 39% of these families rely on the Internet for information.

When asked to share their concerns, 73% of all families reported they are concerned with their family being supported if they need to be hospitalized and if someone they know would be able to stay with them in the hospital (70%). Family members also report being concerned about how they would manage if their loved one with a disability got the virus (59%) and who would care for their loved one if the caregiver got the virus (69%).

Spanish speaking families (67%) reported that they are most concerned about their family member staying healthy. They are also concerned about having enough money to get through this crisis (61%), having enough medication and supplies (53%) and what would happen to their family member with a disability if they were to become ill (57%). In general, 73% of families are concerned about the health of their family member with a disability during this COVID-19 crisis.

When asked what other concerns families had, the following comments were shared:

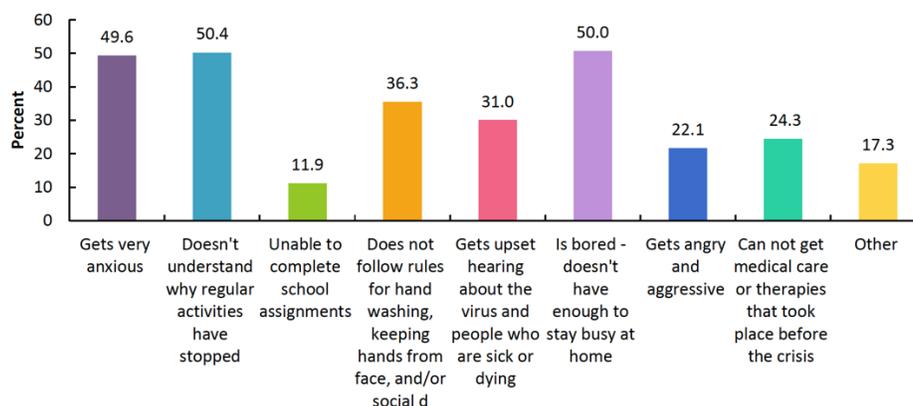
- Day/employment services ended. It is challenging to support family member at home and maintain routine; some also are trying to keep working while supporting family member. This additional challenge allows no break for caregivers - 8 responses
- Worries about adequate support for family member in hospital when person would need a familiar caregiver be there to support – 4
- Challenges with distance learning, distance learning not being equitable, or worry about students falling behind – 5 responses
- Worry about staff who also work other places carrying virus into the home – Or family members who are essential workers and need to continue working outside home – 4
- Concerns about lost work / income for caregiver– 3
- Medicaid denial of routine seizure meds – 2

Of utmost importance, 86% of families reported feeling stress during this crisis. When asked to describe their challenges/concerns, families shared the following:

- Concern that caregiver is in vulnerable category – other health issues of caregiver or worry about what will happen to family member if caregiver gets sick – 6 responses
- Family member with disability frustrated at not being able to get outside or to usual places / people – 5 responses
- No time for myself; no time to relax / exercise; working and managing school and/or full-time care of family member often with multiple family members to care for is daunting - 4
- Concern about death among African American/African community
- My son and I both have COVID-19. I was quarantined and had to be separated from him. My older son filled in and spent time with my son and looked out for him. Now that my son with autism has also been diagnosed, we are all in quarantine. We still have another week of quarantine and he’s on his own. That’s what worries me.
- I am concerned that my daughter or my mother would get sick and I could not go with them to hospital.
- Worry about having a long-term plan for her. I have a lot of anxiety about that.

Families were asked to share information about the how their loved one with a disability is coping with the crisis situation. Figure 2 demonstrates their responses.

Figure 2
Individuals with Disabilities Coping with COVID-19 Crisis



Fifty percent of families report that their family member is very anxious and does not understand the quarantine (50%). Families are reporting that routines are challenging and that their loved one does not have enough work/activities to stay busy at home (50%). Additional comments by families included:

- All things person used to look forward to (and/or supports) no longer available. Doesn't understand why life has changed – 9
- New or increased behavioral issues since crisis (verbal, self-abusive, withdrawing, depression) – 7

- Has limited understanding of how to protect themselves (masks, social distancing, hand washing, etc.) and the seriousness of the matter – 5
- Challenges with distance learning for school age special ed students – 4
- Watching Governor’s daily briefings and explaining that this is happening for everyone to keep us safe helps – 2
- Medicaid has denied prior authorization request for typical daily seizure medication.
- One family member with disability has already been removed by police sent to Butler (home now) The other is extremely Anxious with Behaviors. I'm trying to not show my anxiety but it is exhausting.
- Community workers (counselors) no longer coming. Needs DDD supports. Long term plan with the right approach -- gently (She has autism and need to be understood)
- I fear what the long terms of social distancing will have on him.
- My granddaughter was just approved for a Social and Emotional IEP we were supposed to get it on March 25th. I have no idea what to work on with her since we never saw it.

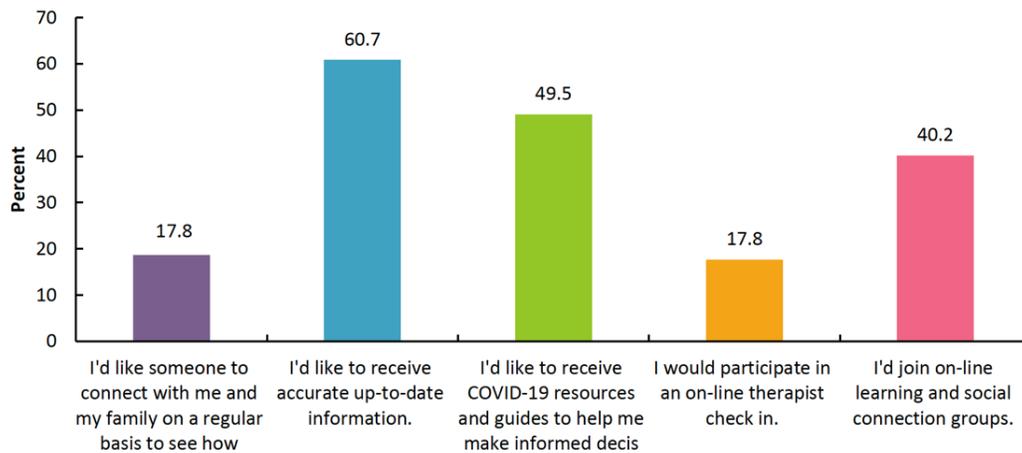
Families were also asked to describe any behavioral changes their loved one has experienced. Twenty-seven responded to the question with 19% of total reporting behavioral changes in their loved one since the crisis began. Some representative comments are as follows:

- Contact with service agency minimal - Employment search full stop. Job developer tried online sessions, but attention is taken by supports needed in a group home.
- I think this change has had a huge impact on all of us and my son is having difficulty with understanding and managing his emotions. Just very stressful for everyone.
- Behaving very badly towards parents and staff. Fighting with us all the time. Needs someone to be able to explain situation in sign language.
- He is constantly asking "when will this be over". "why can't I see my friends and go out" I miss my program.
- We need gloves and masks to be able to go to the supermarket or the pharmacy.
- I would just like to have any support to help with his behaviors. No HBTS services in a year and also no other supports. Very frustrated with the lack of help and support along with the difficulty finding any worker and the time- consuming hiring process.
- Need a trained team of professional to intervene and provide assistance to caregivers and /or respite for my family member with IDD and Mental Disorders

When asked which kind of support they would like to receive, families most frequently cited accurate up-to-date information (60% -- 80% with Spanish-speaking families), followed by COVID-19 resources and guides (50%) and online social connection groups (40%). Figure 3 illustrates family’s responses.



Figure 3
Supports Families Would Like to Receive



In summary, while families report they are managing, they are also reporting that they are experiencing challenges with the crisis situation. They share that their loved ones are having difficulty understanding why they are in quarantine, having enough activities to keep them busy and behavioral challenges for which they need help and support. They are concerned about what happens in the event they or their loved one becomes ill and needs to go to the hospital, specifically if they would be cared for by someone who knows and understands them. Parents comments provide details of their concerns related to access to medical treatment, home supports, availability of medication, the need for social emotional supports and above all the need for accurate information presented in easy to read, understand and in preferred languages.

As a result of this survey the coalition makes the following recommendations to better support the disability community:

1. We all work to ensure that all families, including non-English-speaking families, have reliable, accurate information in forms they can access whether by ensuring Internet access or getting key important messages on Spanish or other language radio/TV.
2. Create and disseminate information about COVID-19 in plain language, including Spanish and in alternate formats, for individuals with disabilities to gain knowledge and understanding of the crisis. Topics should include, but not be limited to, What is COVID-19? What does quarantine mean? Why is social distancing important? What happens if I need to go to the hospital?
3. Ensure that decisions made regarding policies and procedures related to COVID-19, take into account individuals with disabilities.
4. Have clear guidelines on what a family should do if they or their loved one becomes symptomatic or ill with COVID-19.
5. Ensure (or advocate) that hospitals allow the presence of a family member, or service provider, knowledgeable about the management of their care and/or able to assist

them with communicating their needs, for patients who require such an accommodation.

6. Find ways to connect families of individuals with disabilities to mental health and social emotional supports.
7. Ensure that information is available in multiple languages, including Spanish.

