COVID-19: PRELIMINARY AFTER ACTION REPORT

COMPILED BY THE NEW MEXICO GOVERNOR'S COMMISSION ON DISABILITY

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NEW MEXICO AFTER ACTION REPORT: THE DISABILITY COMMUNITY

What did and did not work during the COVID-19 pandemic?

March – December 2020

The COVID-19 Pandemic has had a disproportionate impact on people with disabilities. When looking at how the pandemic has affected New Mexicans with disabilities, it is critical that their voices are centered in that discussion. The After-Action Report (AAR) of the Disability Community's experience is an essential tool to provide information on what has and has not worked for people with disabilities in the state of New Mexico during the COVID-19 Pandemic.

In the Winter of 2020, seven focus groups representing different disability groups were convened by representatives of the New Mexico Disability Emergency Planning Advisory Council (NMDEPAC) and members of the Disability Community. Each group reflected on their experiences during the pandemic over a period of nine months (March to December 2020). The seven disability focus groups were:
1. Cognitive Disabilities
2. Physical Disabilities
3. Blind and Visually Impaired
4. Mental Health Disabilities
5. Deaf
6. Hard of Hearing
7. DeafBlind/Oral Deaf Blind

A total of 51 New Mexicans with disabilities participated. They represented a wide range of ages, races, ethnicities, educational backgrounds, and geographic locations. They discussed their experiences during the pandemic related to technology, healthcare, transportation, employment, education, social experiences, access to food and supplies, housing, and voting. This Preliminary Report is organized around the themes in each of these categories that came out of the participants' reflections and experiences.

New Mexico Disability Emergency Planning Advisory Council (NMDEPAC) is a project of GCD. It is comprised of people with disabilities who provide advocacy, advice, training, and education on disaster preparedness in partnership with state and local agencies, emergency managers, first responders, and disability communities throughout New Mexico. NMDEPAC works on emergency preparedness initiatives before, during, and after a disaster to include individuals with disabilities in all stages of planning and response.

THEMES	• technology • healthcare • transportation • employment • education	• social experiences • access to food/supplies • housing • voting

Each focus group discussed their experiences and the obstacles they faced during the COVID-19 pandemic to meet their daily needs, receive care, and perform their duties as workers, friends, parents, and family members. Here are the common themes that came out of those discussions in the areas of - technology, healthcare, transportation, employment, education, social experiences, access to food and supplies, housing, and voting.

TECHNOLOGY

All focus groups reported internet connectivity and broadband issues, especially in rural areas. People with disabilities often need high levels of data and faster broadband speeds. This is because some disability groups frequently use video-based communication or use programs that require large data transfers at rapid speeds. As a result, people with disabilities often run into data caps and pay a premium for broadband speeds that are adequate at best. When internet connectivity is poor it can interfere with video ASL interpretation and make it difficult to do multiple data intensive processes. For some participants, internet usage must be scheduled between family members who need to participate in work and education-related video meetings.

Many participants expressed that there was a technological learning curve when they started teleworking. They not only needed to improve their technology skills for work, but also to meet daily living needs and participate in the community. There was a preference for virtual conference platforms, such as Zoom and Google Meet, which had better accessibility features than others. There were technology challenges if a person needed additional accessibility features to access websites, especially when the needed accessibility features were not available at home but only at the office. Parents with a disability, such as blindness or a visual impairment, also faced challenges in assisting with their children's education when schools switched to remote learning as the technology was not accessible to those parents for them to provide support. Access to medical care, therapy sessions, and counseling services through tele-health has been difficult due to needing hands on services and/or the inconsistent use of sign language interpreters and/or captions. They were unable to communicate their needs effectively, which created more stress.

Participants in the Hard of Hearing focus group highlighted that an increase in internet needs coupled with a lack of adequate speeds affected their ability to use a captioned phone. Most said they no longer used landline captioned devices due to severe limitations in their internet access. Many of them use the Bluetooth connectivity in their hearing aids or their telecoils with their smart devices to augment their ability to understand what is being said in a phone call and use the applications on their smart devices for additional support.

THEMES

- technology
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HEALTHCARE

In non-COVID pandemic times, people with disabilities face significant disparities in access to healthcare and poorer health outcomes. During the pandemic, these realities were only exacerbated. Participants reported foregoing care, and having services withdrawn or cut back. Many groups discussed how telehealth appointments were inaccessible or inadequate, either because they lacked the appropriate technology or internet connectivity, health professionals and counselors did not know how to use the virtual technology, or setting up accommodations or interpretation was time intensive and ate into the time they had to discuss health concerns.

The Deaf, DeafBlind/Oral DeafBlind, and Hard of Hearing communities had to deal with communication barriers imposed by masks. A person cannot read lips when someone is wearing a mask. Hard of Hearing participants had difficulty hearing sounds through their hearing aids when others wear a face mask. Problems scheduling appointments arose due to limited interpreter availability.

The Blind or Visually Impaired participants experienced increased anxiety and apprehension at the prospect of going to healthcare appointments, because they are not able to see if others are practicing social distancing.

The Physical Disability group reported cancelled physical therapy appointments, difficulties obtaining medical supplies, or not receiving their prescriptions regularly. They encountered durable medical equipment suppliers that were understaffed and not mailing supplies on time. At least two participants with physical disabilities had some problems with heat when they wore masks which impacted the responsiveness of their muscles.

Participants in the Cognitive Disabilities group expressed frustration that their case managers were not easily accessible, and many day-services were closed, or services were curtailed.

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HEALTHCARE

The Mental Health Disability group discussed that they had trouble communicating and expressing themselves in telehealth counseling visits due to the lack of in-person connection. They reported that some therapists terminated services with their clients, and participants did not feel comfortable starting over with a new therapeutic relationship. Participants also highlighted the anxiety and difficulty of getting prescriptions filled. Some experienced increased stigma when they had to fill a prescription for a controlled substance. Others said they had to risk exposure with frequent trips to the pharmacy because they would only receive a 30-day supply of a prescription at a time. During a pandemic when there are heightened feelings of anxiety, participants were still unable to bring their emotional support animals into certain public areas which led to some participants cancelling appointments.

> **Participants in all groups reported barriers to bringing a support person or an SSP (Support Services Provider) with them to medical appointments.**

Participants in all groups reported barriers to bringing a support person or an SSP (Support Services Provider) with them to medical appointments. Some individuals were able to get permission to bring a support person, but others were not, and this created additional stress and anxiety about not getting their health care needs met. Some members of the disability community expressed grave concerns about rationing of care. They feel uncertain that they will get the help they need if they contract COVID-19. They fear that medical professionals will only see their disability and not prioritize them for medical care.

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TRANSPORTATION

The DeafBlind/Oral DeafBlind, Blind or Visually Impaired, and Cognitive Disabilities group reported the most difficulties with transportation. These groups rely heavily on public transportation, city buses, paratransit services, and ride-sharing services like Lyft and Uber. These transportation options are critical, not just to get from A to B, but also in supporting individuals to live independently. During the pandemic, most participants in these three groups reported that they stopped using these services. Some transportation services were operating on a limited schedule and many participants were fearful about being exposed to COVID-19. They did not know how buses and cars were being sanitized or if social distancing would be enforced. Participants in the other focus groups also said they stopped using public transportation and ride sharing services due to safety concerns. Instead of using these transportation services, participants reported they relied on friends, family members, household members, and trusted SSPs.

Participants in the Physical Disability focus group experienced considerable frustration when businesses created an outdoor dining area in adjacent accessible parking spaces. The misuse of accessible parking spaces is already a significant issue, whether it is people without a mobility disability using a space or delivery vehicles occupying accessible spaces. Even though someone with a physical disability has transportation, that transportation is made ineffective when there is a lack of accessible parking spaces.

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EMPLOYMENT

All the focus groups encountered issues with either finding a job, losing a job, reduced hours, or experiencing temporary furloughs. Some of these difficulties were attributed to businesses closing or reducing their work force. Participants in each of the groups also reported that working from home required adjustments, and some struggled to get the same support and accessible technology they needed at home as they had in the office. Members of the Blind and Visually Impaired community had to adapt to new job duties and new responsibilities because of a quick transition to remote work. They needed to adapt to the available assistive technology they already had at home rather than better, more accessible technology they had at their work site.

Poor internet service also created problems for those working remotely. Data use caps are an added constraint with the increase in video conference meetings and remote learning for school-aged kids. Not having the right technology, adequate internet bandwidth, or sufficient data plan created anxiety that these access barriers would affect the quality of their work and would reflect poorly on their job performance.

Participants in the Cognitive Disabilities focus group reported significant job losses or reduction in hours. They also reported difficulties in getting connected to employment support services, long waitlists, and infrequent contact from job coaches. A participant in this group emphasized how employment provides opportunities to socialize and can be a lifeline.

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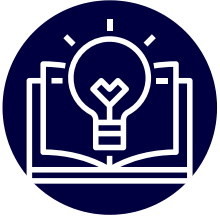>
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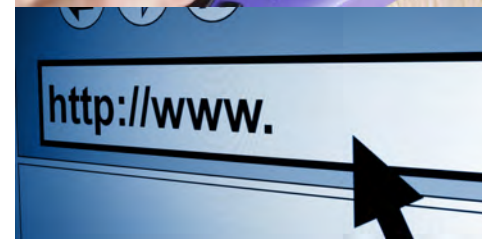
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EDUCATION

Remote learning is new territory for parents, teachers, and students. They expressed frustration with the lack of broadband speed, internet access, and connectivity issues. The use of videophones and virtual platforms requires higher data usage which created problems as work and school needs competed for limited internet bandwidth and data.

Parents of children with disabilities were tasked with providing accommodations, as schools were unable to provide 1:1 support during the pandemic. A parent stated they had to attend their child's virtual classes to write up notes, as their child has dyslexia and dysgraphia. There were difficulties in navigating Zoom technology for some children with disabilities, and parents needed to be available to help which took away from their ability to work from home.

Access to braille and assistive technology is essential for students who are blind or visually impaired. New educational apps were not always accessible, and students did not receive hands-on learning experience to use braille or other assistive technology. Parents who were either blind or visually impaired also had difficulty supporting their children's education due to inaccessible technology.

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SOCIAL EXPERIENCES

Participants in each of the focus groups touched on themes of isolation and depression, loneliness, challenges to maintaining COVID-19 safe practices in social situations, and feeling a loss of control in their daily lives. Individuals in the Cognitive Disabilities group expressed how social isolation contributed to feelings of mental fatigue, depression, and anxiety. They also stressed how job loss contributed to social isolation. For some, having a job was the main outlet for social opportunities. The Mental Health group also discussed some fear around being overwhelmed by emotions. Both groups highlighted successful coping strategies they used, such as self-care, using technology to stay connected, and engaging in creative arts and outdoor activities.

> **Participants in each of the focus groups touched on themes of isolation and depression, loneliness, challenges to maintaining COVID-19 safe practices in social situations, and feeling a loss of control in their daily lives.**

Participants in the Deaf group discussed the impact of social distancing on Deaf culture. Deaf culture includes the tendency to hug or tapping someone on the shoulder to get their attention. They expressed feelings of fear, worry, and anxiety when it comes to trying to follow social distancing rules within Deaf culture. Participants also reported feeling depressed and talked about how the pandemic transformed their routines and limited their outings.

Masks imposed communication difficulties for individuals in the Deaf and Hard of Hearing focus groups. Lip reading cannot be done when people are wearing masks, and masks make it difficult to gauge how someone is feeling. Participants in the Hard of Hearing group reported that there have been instances where group members were shouted at, or people pulled down their masks, potentially exposing them, because they thought that this was the only way to communicate.

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SOCIAL EXPERIENCES

Participants in the DeafBlind/Oral DeafBlind focus group reported that they had to adapt in many ways. It took them a while to get used to social distancing and to build trust with their SSPs to ensure that they were following social distancing rules. They are very cautious to ensure that they wear gloves when they communicate with their SSPs. In Deaf/Blind culture people hug each other in greeting. Participants said they are struggling with not being able to hug and interact with others. This is exacerbated by the cancellation of family gatherings, events, and meetings. Some of participants mentioned that they felt depressed because of the isolation caused by the public health orders. Some reported that they had suicidal thoughts, but with support realized that they are strong enough to get through this crisis. Most of them feel that their friends and families are being helpful to reduce their depression and anxiety.

Participants in the Blind and Visually Impaired group said they cannot gauge whether someone is maintaining social distancing of 6-feet or if someone is wearing a mask. They also had concerns about their service animals contracting the virus as they rely on them for their social independence. Some individuals said they felt socially isolated, but they had hope for the future.

ACCESS TO FOOD/ MEDICAL SUPPLIES

Participants in each of the focus groups reported that they had access to food and supplies. This was in part due to support systems in place, particularly for participants in the Physical Disability, Blind and Visually Impaired, and DeafBlind/Oral DeafBlind focus groups. Access was not without its frustrations and limitations. Some of these difficulties included - contending with limited store hours and long lines, inability to get everything one needed through on-line grocery services, increased cost of food delivery services, and limited availability of toiletries for communities that were relying on food box distributions.

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ACCESS TO FOOD/ MEDICAL SUPPLIES

In addition, DeafBlind/Oral DeafBlind participants who received food stamps reported a lack of communication about why their food stamp amount was increased during the pandemic.

One problem was reported by the Blind and Visually Impaired group when they found that stores arranged for aisles to go in one direction. Stores used paper placards to indicate the direction of traffic, but this was not an accessible form of communication. Someone who is blind or visually impaired would either need store personnel to guide them through the aisle appropriately, or the placards would need to have large print or braille available. However, using accessible placards that require touch could create anxiety for these individuals due to fears of COVID-19 exposure. Training should be provided to shopping assistants and retail store employees on how to work with people who are blind and visually impaired, and how to provide an accessible experience so they can shop independently. It is important to keep in mind that people who are blind and visually impaired cannot gauge whether they are staying social distanced. In addition, someone who is blind and visually Impaired uses memorization of where most things are in an environment, so if things get moved or are put in the wrong place, then this creates problems in finding their way.

Participants in the Deaf focus group also encountered significant communication barriers. Masks made reading lips and facial expressions almost impossible to use or see. Participants said they immediately went straight to paper/pen or their phone to communicate with others. In addition, participants reported that when they had food or meals delivered to their home and the driver would get lost, they could only use text messaging to communicate with the driver to give them directions. The pandemic has increased communication barriers with mask wearing, and they reported that others have become more impatient.

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HOUSING

Participants expressed frustration and anxiety over not being able to pay their rent. The DeafBlind participants described problems with the money order system and fell behind in their rent payments. The Mental Health group described how shortened banking hours made it harder to deposit their money and pay rent. One participant described difficulty paying for medical bills and rent on a fixed social security disability income. The participant was able to avoid being evicted by obtaining rental assistance.

Some participants in the Cognitive Disabilities focus group reported that people in their community received eviction notices. They were able to arrange flexible rent payment programs to help stabilize their housing situations.

VOTING

> **In-Person voting did not feel safe**

Most of the participants in each of the focus groups voted by absentee ballot. The political climate and COVID-19 fears created stress and anxiety for many in the groups, and in-person voting did not feel safe. Assistance from close family members or friends was critical for most groups to complete the voting process.

Participants in the Blind and Visually Impaired group were able to vote absentee with an electronic ballot marking tool available in New Mexico. They experienced some difficulty with the tool. For example, information about amendments to the state constitution and bond issues were not accessible, and one participant kept receiving error messages. These issues were reported to the Secretary of State and were resolved.

Participants in the DeafBlind/Oral DeafBlind group voted in-person and by mail, and some were unable to vote.

SUMMARY

Listening to people with disabilities and their lived experiences in this pandemic highlights the tremendous need for reliable internet connectivity, equity and accessibility in telework and remote learning environments, and greater attention to how barriers in communication and isolation exacerbate disparities in health and wellness for people with disabilities.

It is clear, we need reliable and fast internet without data caps. Throughout the pandemic, it is the internet that keeps people connected, allows them to work, and go to school, attend to their health needs, and order food and supplies. Telework and remote learning adds to the burden on home internet plans, but people with disabilities additionally need the internet to communicate through video-based programs or other communication programs that require large amounts of data. A reliable and fast internet improves access to necessities such as work, food, education, healthcare, and social connection. It will also ease the sense of frustration, loneliness, isolation, and fears that the pandemic heightened for the disability community.

The pandemic also has had an outsized impact on the employment and education of New Mexicans with disabilities. All the focus groups encountered issues with either finding a job, losing a job, reduced hours, or experienced temporary furloughs. Many participants discussed needing additional support. For those who are working or learning from home, the accommodations or assistive technology that was available at the office or at the school, are not available at home. Virtual platforms and educational tools are not always accessible. People with disabilities devised work arounds to be able to do their jobs and participate in class. Parents discussed the monumental task of not only working from home but also providing one-on-one educational support for their children with disabilities.

Without a doubt, disconnection, barriers in communication, and isolation have had a disparate impact on the health and wellness of people with disabilities. Especially for residents in rural areas, limited transportation options for people with disabilities that felt COVID safe complicated making doctor appointments, meetings, or taking care of personal needs. Participants had to rely on trusted family or friends for transportation assistance, and some participants postponed healthcare appointments. Feelings of loneliness, anxiety, depression, and suicidal thoughts were discussed in connection with social distancing and isolation. There is also increased anxiety and fear about COVID exposure risk in public. This is especially true when someone does not know how to interact with a person with a disability, or you cannot see if someone is maintaining social distance, or you are unable to ambulate to avoid someone without a mask.

The experiences shared during the focus groups emphasized the challenges and the unique impact that the pandemic has had on people with disabilities. Participants also highlighted that every day, with or without a pandemic, people with disabilities are creatively problem-solving around barriers. As we learn what has and has not worked during the pandemic, the solutions to the challenges presented must include people with disabilities.

ACKNOWLEDGEMENTS