



What's on the Other Side? The Impact of COVID 19 on Organizations Serving People with Disability across India

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Abstract

As organizations serving people with developmental and psychosocial disabilities react and adapt to the realities of a global pandemic, how are they faring from an economic, programmatic, and workforce perspective? This article reviews the current circumstances for a number of such organizations, provides a snapshot of current organizational health and raises questions about the future condition of such essential and vital supports and services across India when the nation emerges from COVID 19.

Keywords: *developmental disabilities, survey, impact, organizations, COVID, staff, funding.*

Introduction

In June of 2020, a series of dialogue sessions were held with families, people with disability, and organizational leaders to discuss the impact of the global pandemic. The results of these sessions were summarized in a paper entitled *The Impact of COVID 19 on People with Developmental Disability and their Families: Perceptions of Families, Allies, Advocates and Professionals* (Neuville et al., 2020). There were some surprisingly positive impacts noted, as well as some real concerns and questions about the future. Many family members expressed the perceptions that their sons and daughters were contributing so much to family life during lockdown, and in unexpected ways. With the temporary absence of domestic help, family members were pitching in together, and that included family members with disability. As day centres shuttered their physical sites indefinitely, they substituted online gatherings and activities. Both families and professionals were generally surprised and pleased with how quickly people

had mastered the technology and were fully engaged with it. In some ways, the digital divide between people with and without disability (Macdonald & Clayton, 2013) may be lessening, to some degree, although this needs to be explored by further enquiry and research.

A number of deeply concerning questions were raised within this paper, and one was specifically about the future of organizations serving people across India, specifically those with developmental or psychosocial disability. Keystone Institute India launched a study to further explore this issue. As is well known, the formal support system for people with developmental disability across India is delivered by a patchwork of organizations (Girimaji & Srinath, 2010), often founded by family members, and funded by a combination of participant fees supported by proceeds of fundraising and donations, including an increasing reliance on corporate social responsibility initiatives. The authors are

concerned about the strength and capacity of these organizations to withstand stressors posed by the pandemic, and decided to more fully explore these issues. Will organizations emerge from the pandemic at all? Will they emerge changed in some ways? What can families and people with disability expect once the COVID 19 pandemic and its impact lessen in terms of organized supports and services? The health and well-being of disability-serving organizations will impact the health and wellbeing of those impacted by disability (Lang, 2000).

Methodology

A survey consisting of twenty-three questions was developed and tested by the authors. The survey consisted of basic demographic information from each respondent organization, including size, clientele, reach, staffing and types of services offered. Probing questions about the impact of COVID in terms of reductions, modifications, and growth in all service types were included, as well as queries on the impact on the workforce, staff retention and payment, and level of financial support pre- and post the advent of COVID and the lockdown in March of 2020 and onward.

Organizations were selected from Keystone Human Services International's network of allied organizations across India. The survey was disseminated via email to just over 200 individual organizations, representing organizations from across India. Responses to the survey were unidentified and anonymous to encourage honest responses, and a 26% response rate was achieved in fifty-two returned surveys. It should be noted that organizations were asked to engage senior leaders within the organization staff to complete the survey, to assure that the respondent has sufficient knowledge of funding, service measures, and staffing issues.

It is acknowledged that fifty-two organizations, all of which are engaged in some way with the organization conducting this survey (KHSI), do not represent a random sample of organizations. However, valuable information can be gained about the organizational health and future prospects for these fifty-two

organizations, which may be predictive about the condition of such organizations now and emerging from COVID, may raise important questions, and may offer up invaluable strategies about bolstering support to people with developmental and psychosocial disabilities and their families.

Impact of COVID 19 on Services of the Organizations

The survey examined the impact of COVID 19 on the services provided, economic and financial status, workforce, and perceived morale of the organizations. Data collected through the twenty-three questions were supplemented by open-ended comment sections after each section, providing rich context beyond the numbers reported. This section will outline the major findings of the survey, interspersed with commentary and important areas for further study. Overall, it is commonly known that many organizations have reduced services dramatically during the pandemic (Courtenay & Perera, 2020), but combined with the information about sources of funds, workforce changes, and the overall perception of organizational health, it is hoped that this information will energize advocates and others to raise awareness about the significant challenges being faced by organizations which are essential to people with disability and their families, to prepare for possible long-term service changes, and to support the innovation of currently organizations to apply their nimbleness of approach to some of the most important goals shared by people with disability, their families, and civil society (Rochet, Keramidias & Bout, 2008).

Service Closures and Service Reductions

The information about service disruption is not surprising, but still sobering. Only a mere 3.6% of fourteen service types across fifty-two organizations have been able to continue their operations without disruption. A staggering 72% of all services types across all organizations are reported to have ceased operations entirely, or reduced them. The developmental impact of this on people with disabilities and their futures are unknown, but an issue for further study. Of the various service types, the hardest hit by service

closure are centre-based employment services and community-based rehabilitation services, with deep impact also in centre-based and home-based Early Intervention. Early Intervention is a lifeline for many families and a service known to have high positive impact throughout the life of the child (Guralnick, 2008). Nearly half of all Community-Based

Rehabilitation programs, an essential service across rural areas and amongst very vulnerable populations (Mauro, Biggeri, Deepak & Trani, 2014), are reported as not operating at all, while the vast majority of the remainder CBR services. Information on specific services is presented in Table 1.

Table 1 Impact on Services

Service Type	NOT operating	REDUCED to partial operation
Centre-Based Therapy Services	29%	60%
In-Home Therapy Services	27%	51%
Centre-Based Education	34%	51%
Centre-Based Vocational	55%	32%
Centre-Based Early Intervention	47%	42%
Home-Based Early Intervention	32%	44%
Centre-Based Mental Health	34%	38%
Residential Facilities	33%	17%
Advocacy Services	23%	38%
Community-Based Rehabilitation (CBR)	48%	44%
Research	29%	36%
Parent Support	9%	36%
Home-Care	24%	29%

The definition of ‘partial operation’ was not given in the survey, so the degree to which services were reduced is unclear, but the table above indicates that many services were reduced to partial operation.

Innovation through Service Adaptation

Interestingly, 20% of service types across all respondent organizations indicated they were operating fully, but with significant modifications. This likely means that organizations were able to adapt and modify services to be delivered in alternative ways that did not involve face-to-face delivery. Open-ended responses indicate that modifications included classes, meeting, counselling, and teaching sessions taking place over the telephone, email, and through online conferencing. This raises questions over the efficacy of these kinds of alternative delivery methods, and what is both gained and lost by these methods. It also raises the question of whether the benefit is limited to families and individuals who are well

resourced and better able to afford access to technology. It also raises questions for the vast numbers of people with disability across India who do not have engaged families and may not have access to these modifications at all. One organization noted that they have experienced a reduction in the numbers of people they serve, as many belonged to migrant families who returned to the home villages because of job loss in urban areas. So even organizations which have been able to provide full, modified services during the pandemic may be reaching far fewer people. In fact, one organization noted that they have lost track completely of many of the children and families they serve due to migrant families relocating. This issue is supported by the survey question pertaining to reductions in numbers of people served, as 59% of organizations have experienced a reduction in the number of people served, with 18% of organizations recording a reduction of 75% or more.

Level of Financial Distress

It is well known that many organizations serving people with developmental and psychosocial disability are small, regional, and operate in the best of times with a thin financial margin (Baviskar, 2001). The survey reveals that, indeed, organizations are, in general, experiencing life-threatening financial positions.

- 72% of organizations surveyed have experienced a reduction in funding by an average of 46% of pre-COVID funding
- 60% of respondents classify the financial impact of COVID 19 as NEGATIVE, while 18% say it is VERY NEGATIVE

Of course, reduced funding is accompanied by reduced costs in some situations, as funds may not be expensed because some services are not being provided, or they are being provided at less cost through telephone or distance. The overall financial loss of each organization, on average, is reported in Table 2.

Table 2 Financial Loss

Financial Loss to date (Post-COVID)	Percentage of Respondent Organizations
None	7%
1-20%	24%
21-40%	20%
41-60%	24%
61-80%	22%
81-100%	4%

This translates to a picture of uncertainty as to how much long-term damage is being done to the organizations, and whether organizations will emerge with a significant capacity to reorganize, transition back to operations, and maintain fiscal viability. Understanding the impact of this requires us to explore the ways organizations receive funds and the impact of funders and payers.

Fees charged to individuals and families often make up a part of the financial picture, most often supplemented in large or small part by government allocations, corporate or individual donations, and grants. Organizations spend a significant time pursuing funds via campaigns

and activities, and they spend time raising awareness of their organization through public activities. One would expect these activities were reduced, and it could be hoped that donors and organizations would make up the difference to keep these organizations viable and operating, or ready to resume operations quickly. In fact, the reports from the respondent organizations paint a grim picture of the funding environment as is shown in Table 3.

Table 3 Impact on Funding

FUNDING SOURCE	Impact
Private pay from families and service participants	75% have seen a funding decrease
Donor Funding	60% have seen a funding decrease
CSR Funding	53% have seen a funding decrease
Government Funding	28% have seen a funding decrease

Adding to this grim picture, donors and funders are not continuing past levels of assistance and support. The data also shows that, on average, 24% of the funds they are counting on have been deferred for later payment.

Human Resources and Staffing is Important to Recovery

It is well known in all sorts of human services that the organizations are only as good as the skill and presence of excellent and well-suited staff (Gomes & McVilly, 2019). The survey looked to gain information about whether there is a significant loss of staff resources, or whether the work force remains available to resume services post-COVID, in whatever form such services take. Given the amount of financial distress and service disruption shown above, it would be expected that many staff would be lost to the organizations at this point. However, the data presented in Table 4 shows organizations are working hard to retain their work force. While more than half (65%) of the organizations have not temporarily laid off any staff at all, the ones that have done so largely plan to restore them to employment within 1-5 months.

Table 4 Possibility of Reinstating Laid off Staff

Expected time of reinstatement of temporarily laid off staff	Percentage of respondent organizations
1-2 months	11%
2-3 months	6%
3-5 months	33%
Don't know	33%

Table 5 shows that almost 70% of organizations have not ended the employment of anyone at all due to COVID impact, with 20% of organizations eliminating their workforce level by less than 20%.

Table 5 Loss of Employment

Efforts have been made amongst most organizations (60%) to continue to pay their staff at full salary, with 16% reducing salary levels by less than 20%, but another 14% reducing salary levels of staff by 80-100%. This is presented in Table 6. Almost 70% of organizations continued to pay their staff without having to defer their payments. Table

Range of Elimination of Workforce	Percentage of respondent organizations
0% (none)	67%
1-20%	20%
21-40%	6%
41-60%	2%
61-80%	2%
81-100%	2%

7 presents the status of deferral of staff payments in the said organizations.

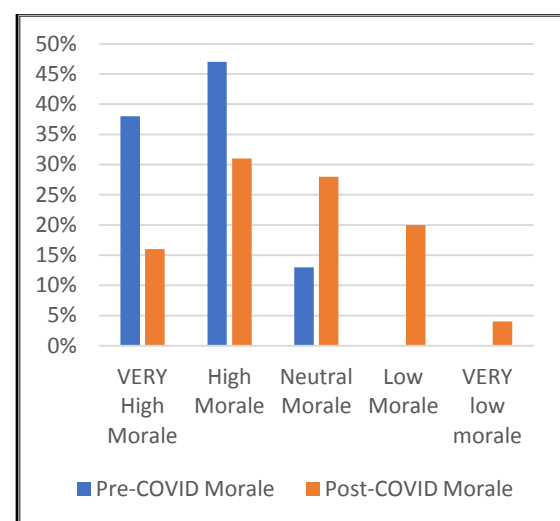
Table 6 Impact on Salary – Reduced Payment

Percentage Range of Staff Impacted	Percentage of Respondent Organizations
81-100%	14%
61-80%	2%
41-60%	6%
21-40%	2%
1-20%	16%

Table 7 Impact on Salary – Deferred Payment

Range of Staff Impacted	Percentage of Respondent Organizations
81-100%	4%
61-80%	4%
41-60%	4%
21-40%	0%
1-20%	18%

Several assumptions can be drawn from this information. Although organizations appear to be making strong efforts to minimize the financial impact of the downturn on the staff, the loss of revenue to organizations and the uncertainty of how long this can be maintained must weigh on the minds of all, likely impacting the morale of the organization. Of course, many other factors also impact morale; however, the survey invited respondents to characterize the morale level of their organizations, pre-COVID and post-COVID. The results presented in Figure 1 suggest that, although the pandemic has induced an overall decrease in morale, many disability organizations still see their morale as high and are looking for more hopeful futures for the people they serve and for their own organizations.

Figure 1 Organizational Self-Assessment of Morale

Discussion

The data illustrates that organizations have worked to adapt and shift how they work in

response to the sudden onset of restrictions put in place in March of 2020 due to COVID 19. Many have been able to explore new ways of working, and new ways to touch the lives of the families and people they serve. From the comments in the open ended questions, it appears that many organizational leaders have been surprised at and pleased that these adaptations have been successful, to a degree.

The financial predicament that many organizations are facing as revealed by this survey are complex, and reflect the overall economic downturn. It could be surmised that donors, both individual and corporate donors, are not maintaining their prior levels of support due to their own reduced economic circumstances, or perhaps the giving has been redirected to other people and projects with a direct link to alleviating the suffering and hardship caused by the disease itself, the resultant economic hardships faced by many people, or to bolster other sectors such as poverty reduction and health care, which may be prioritized. These are questions which deserve a closer look, as without intervention, these vital organizations may fail, and with such failures will come great impact on the lives of people with disability and their families. By the survey, most organizations perceive that the problems they are experiencing are survivable, but deeply challenging. However, the data in this survey does raise concerns about the level of threat to organizations which were already operating with a thin margin before COVID, and may have already been fragile in a financial sense.

Another area deserving of more attention are all the ways that organizations are adapting and changing to provide services through technological means. Many, but not all the organizations surveyed are primarily located in urban or semi urban locales, although many have small rural components. It would be extremely important to see how rural beneficiaries were able to tap into such alternative ways to interact, or whether they were left out of this. It is hard to imagine that the infrastructure and teaching that would be required in such places have been put in place. Across the world, education for children has been changed to distance platforms, and

the early indications are that such education is not resulting in positive outcomes for students. The same scrutiny should be given to the alternate distance course and classes being offered to people with disability over smartphones and computers, and this is a recommended suggestion for more study. Are people with disability really and fully benefitting from these newly introduced methods? How do these methods compare to face-to-face competency enhancement strategies? Are the outcomes as good, better, or worse?

Another area of discussion is that these surveys represent the perspectives of organizations as reflected by the person representing the organization. Similar work should be done to understand more fully the perspectives and positions of people with disability, and those closest to them. For those who have received modified and adapted services, how has that experience been? It is certainly possible that services may never return to how they operated pre-COVID. In one sense that means that many of the modifications and strategies may continue for many other reasons. Perhaps they are less expensive, perhaps they are more convenient, and perhaps they are more efficient and effective. In any case, the effectiveness of such 'distance' services in assisting people with disabilities to have full and rich lives needs to be assessed.

Conclusion:

It is clear that the positions of the organizations that participated in this survey

"Our situation at present is extremely unsure. But, we've got to carry on, thinking positively, supporting our students and parents to the best we can. Our team is dependent on us, they have put in dedicated work for 8, 10, 15 years. It is our duty now to not let them down. They are, in fact morale boosters in this difficult time!"

are dramatically different from early March of 2020. The sudden changes in allowable activity, the extended lockdown orders, the health care crisis and the associated economic

downturn was unanticipated and required quick action. It certainly seems that, in general, organizations adapted with innovation and nimbleness to keep their organizations afloat and to continue to support the people they serve as much as possible.

It is also clear that the impact on the organizational health is significant, crosses the financial, workforce, and service domains and represents a real threat to people with disability across India. Large scale failure of these sorts of organizations would be devastating, and funders, donors and government must be made aware that services to people with developmental and mental health disabilities matter a great deal. Suffering silently is not a good strategy at this time, and a strong case must be made for supporting these organizations.

With all change comes opportunity, and there is also an expectation that the organizations which emerge from the other side of the pandemic will be in a unique position to make

the changes which have been so resistant in the Indian scenario. The possibilities are alive for rebuilding services in new ways that are more inclusive, more integrative, and more effective – services that truly uplift people with disability out of oppression and marginalization.

Disability-focused organizations may well be in an excellent position to work alongside people with disability to show, once and for all, that there is room for all people to live well within society.

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Conflicts of Interest:

The authors declare that the research review was conducted in the absence of any commercial or economic associations that could be construed as a potential conflict of interest

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