

The Impact of COVID-19 on People with Developmental Disability and their Families: Perceptions of Families, Allies, Advocates and Professionals

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Keystone Institute India (KII) holds a unique position to offer some observations about the impact of the COVID-19 pandemic on people with developmental disability. In addition to working closely with a network of organizations and families across India, KII hosted three study groups and a forum over a series of video calls with 104 advocates, activists, families and organizational leaders from 15 different states comprising all regions of India. The original purpose of three of those forums was to discuss the experiences of the participants during the lockdown phase of the pandemic (April 2020), using Social Role Valorization as a lens for discussion. The fourth forum included a wider audience, addressing issues of current concerns from a national network of leading advocates, activists, family members and professionals. The following major themes were drawn from the meetings.

Major Themes

The “lockdown” has resulted in a lengthy period of much narrower life experiences. People who attended programs during the day, both adults and children, have not had access to the regular structure of such programs, and access to the community has been greatly reduced.

1. The ‘Digital Divide’ has lessened

People with developmental disability have often been left out of the explosion of technology tools over the past 20 years. As a result, many of the social and learning platforms available to typical citizens have not been widely available to people with significant disability. This has often placed such persons even further behind in their access to relationships, opportunities, and personal possessions, including mobile devices and computers, considered essential to having a good life. The lockdown has caused many special schools and specialized day services to transition to online formats. Parents and teachers note that they have been often amazed at the willingness and ability of people with developmental disability to attend to online learning, respond to such teaching mediums, and adapt to all sorts of relational experiences over video and social media platforms. This poses potential gains in both the perceptions of people with disability in the eyes of others as well as competency gains which can serve people well.

2. Increase in Developmental Expectations and Performance

Many adults and children with disability have exceeded all expectations and shown remarkable competencies and resilience, as reported by families. Belying common expectations, adults and children with disability have stood up to provide crucial support within their families by taking on household chores and sharing responsibilities as well as to adapt to new ways of learning and engagement.

3. Impact on Family Life

Many families reported a strengthening of family ties as members with disability are more fully appreciated and contribute to household life. The absence of household assistance (due to household aides being also sequestered and away) has created opportunities for all families to manage households together, with all contributing to the day-to-day tasks that many people of moderate and high economic means have not been expected to participate in. One can imagine the toll this pandemic is taking on families who live with a lower socioeconomic status. The impact of loss of income, instability of housing, closure of most supportive programs, weakening of organizations serving such families, and despair of relief in the future are the obvious impacts in urban areas.

4. Multiple Jeopardies

Many people with disability and their families find themselves surrounded by danger not only from the pandemic but also other issues which are much more serious when combined with the pandemic. For example, poverty, addiction, crime, and domestic violence may increase when job loss, sickness, and economic downturn happen. Add to these that existing social and religious tensions are heightened, and groups of people seek to blame other groups of people (e.g. certain minority groups, migrant workers, health care workers) for causing or spreading the virus. Members of such groups who also have a disability can expect even poorer treatment at the hands of society. It is assumed that many formerly employed people with disability have lost their employment due to the closure of hospitality, manufacturing and travel industries, where many such people are employed.

One can also expect that those people with disability are at especial risk once admitted to hospital with symptoms or without, as visitors and advocates will likely be kept away, and people without the ability to stand up for themselves are overwhelmingly vulnerable to neglect, abuse, medical errors, and disparate or no treatment. These are dire and predictable consequences, and anecdotally we are learning of instances where primary parental caregiver(s) have been hospitalized, leaving a person with a disability alone, undefended and potentially abandoned.

5. New recognition of the dangers of congregate living

As India struggles with the sometimes duelling issues of a strong national commitment to inclusive living and the demand from government and families for the creation of large congregate living arrangements, COVID-19 gives another reason to avoid the dangers of large congregations of people in institutions. Little data is available at this point, but we do know that, in general, the aged care homes, prisons, and other congregate facilities have found it impossible to control the spread of the virus. This will be true moving forward as this sickness and others that follow will impact residents of such places disproportionately. This results in all sorts of other problems, not the least of which is the emotional, physical, and psychological impact of being trapped in such settings with few outside eyes which can monitor the conditions and report on them.

6. Weakening of Supportive Services

A patchwork of NGOs, Trusts, and Societies, many founded and operated by families, have often comprised the sole source of organized services for people with developmental disabilities. Such services, mainly facility-based, and funded by a combination of private-pay and donations, ceased functioning during the lockdown. Many have adapted by providing all sorts of ways to keep supporting their clientele through distance means, food provisions, online classes and specialist services. However, it appears that many such organizations may not reopen, or may reopen with weakened programs. Income loss for such programs has been significant, and donors may redirect funds towards direct disaster recovery. Those organizations that have been unable to pay their staff may be unable to rehire them later, and some may never reopen. This can be both a threat and an opportunity.

7. Shared Values and Community Linkages

Some of the most compelling responses to the pandemic were the person-to-person helping forms described within our sessions. The urge to reach out to vulnerable people who have no support has led to the quest for creative chains of communication and informal networking among individuals, families, and agencies, thus forging new partnerships and recognizing strength from unifying efforts and resources. Many of these are highly informal helping forms, person-to-person, and quite different from organizational efforts.

The themes show us that this is a time of both great threat and great opportunity. On the one hand, people who were already more vulnerable owing to disability, socioeconomic status, lack of opportunity and access to technology, and many such social inequities, faced heightened vulnerability and marginalization in the face of the lockdown. There has also been evidence of unexpected gains and revelations about people for whom expectations have historically been low or even absent. Many existing service agencies – non-government, family-run, or facility-based – face the imminent threat of scaling back or closing down owing to resource loss. The results of this could be disastrous for people with disability with weak support systems, and could also spell great opportunity to redesign support, especially daytime support, to be more individualized, relevant, and integrated into typical life and meaningful days. Furthermore, from this, several unanswered questions remain and are outlined. These will be important answers to gain, as understanding the impact will be the key to harnessing the learning from it and even building back better.

Further Questions for Study and Action

1. What have the direct and indirect impacts been on institutions and congregate care facilities that provide residential services? This includes infection rates and death rates from all sorts of private and public shelter homes, as well as government mental hospitals where such a high proportion of people with developmental disability reside.
2. For migrant families who have returned to their homes, what services are in place for them? What is the need for fortification of support in places where few such services exist, but there may be an influx of people with disability who are also unemployed and in need of all sorts of social support.
3. How have people with developmental disability been treated within the healthcare sector, especially those who have suspected or confirmed COVID-19? What sorts of hierarchies and protocols have been used to decide who gets treatment and who does not? Over the next

weeks, as COVID-19 cases continue to rise in some areas, powerful advocacy will be needed to protect the lives of people with developmental disability to assure they are not 'triaged' out of treatment due to their disability.

4. What has been the impact on the employment of people with developmental disabilities?
5. What are the real impacts on service organizations such as NGOs, special schools, and other such services? Will they reopen, and how, have they retained staff, what is their financial position, what threats and opportunities are they facing?
6. In light of the recent natural disaster event in coastal areas in the east, what has been the specific impact on people with disabilities, and what is immediately needed for such people and families?
7. To what extent have people with developmental disability been able to access basic necessities such as food, day-to-day support medicine, health care and other such essential support services?
8. What has been the impact on economically and geographically diverse families and other caregivers of people with disabilities?
9. To what extent has the predictable impact on people with developmental and other disability been highlighted by local and national print and social media, and if so, to what extent?
10. How have government relief packages in response to the pandemic accounted for people with developmental disability? Have the needs of such people explicitly been addressed, and if not, what advocacy is necessary to assure that this population is not overlooked in economic and social relief programs?

The answers to these questions will raise awareness of the realities faced by people with disability and their allies during this extraordinary time of peril, and stimulate action which will address real needs, provide safeguards for the present and future. It is to be hoped that this set of challenges will provide opportunities for the continued progress of Indian citizens with developmental disability towards equity and full citizenship, as well as full and meaningful lives.

Keystone Institute India (KII) is a values-based national training institute designed to improve the lives of people with disability across India and to fuel a change movement on a national level, working toward a more inclusive, just Indian society where all are valued and all belong. The work of KII serves as a catalyst for the development of supports, services, and initiatives, which better safeguard vulnerable people, establishes thinking which works towards full citizenship and full lives, respects the voices and perspectives of people with disability and their families, and facilitates India moving toward a society where all have possibilities and potential, and all matter.

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