



CONSIDERATIONS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY DURING COVID-19 OUTBREAK

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ABSTRACT Corona Virus Disease (COVID-19) has affected all groups in society. Disabled individuals especially intellectual disabled individuals are more vulnerable to its physical, mental, emotional, psychological and social impact. World Health Organization (WHO) and United Nations International Children's Emergency Funds (UNICEF) has also issued their disability consideration guidelines. But these guidelines cover all disabled individuals and elaborate various preventive measures required to mitigate the impact of such infection. Although less is known about the virus and no vaccination has developed till date, prevention is the only measure to protect oneself from contracting such infection. Individuals with Disabilities other than Intellectual Disability has normal cognition level, which helps them in understanding and following the guidelines in less problematic way as compared to intellectual disabled individuals who either are completely dependent on their parents or caregivers or need intermittent or extensive support in performing activities. The role of various stakeholders like Family, Government, Health care professionals, special educators, Community workers, Disability Working Organizations hence become important to provide required support to the individual and his/her family during this time of pandemic. Discussed considerations will not help PwID in this time of pandemic but will also prepare all stakeholders for upcoming such pandemics and will equip them with better planning and timely execution.

KEYWORDS : COVID-19, WHO, UNICEF, Pandemic, PwID, Stakeholders.

Background

The outbreak of Corona Virus Disease (COVID-19) has been declared a Public health emergency of International Concern (PHEIC) and the virus is now a global pandemic, spreading in many countries and territories. While a lot is still unknown about the virus that causes COVID-19, we do know that it is transmitted through direct contact with respiratory droplets of an infected person (generated through coughing and sneezing). Individuals can also be infected from touching surfaces contaminated with the virus and touching their faces (e.g. eyes, nose, mouth). While COVID-19 continues to spread, it is important that communities take action to prevent further transmission, reduce the impacts of the outbreak and support control measures. (Pacific Disability Forum, 2020).

World Health Organization (WHO) in its report "Disability Consideration During the COVID-19 outbreak has described more significant impact of this pandemic on Persons with Disability and discussed measures to mitigate the impact of this pandemic.

A finding published in Disability and Health Journal in late May, states that Individuals with Developmental Disabilities are significantly more likely to die if they contract COVID-19. According to such report fatality rate among Intellectual and Developmental Disabilities (IDD) within age of 18-74 was 4.5 percent (Mozes Alan, Health Day Reporter). Death rate was also found to be high in individuals with such disabilities having age 17 and below, whereas the death rate was same in individuals with or without disability having age 75 years and above. According to Scott Landes, "if 1,00,000 individuals with IDD got contract with COVID-19, 4,500 persons are expected to die, whereas if 1,00,000 individuals without IDD contract with COVID-19, only 2,700 persons are expected to die." These figure shows the difference in death numbers which is 1,800 more people with IDD are expected to die. These figures are supported by a NEWYORK STUDY by James Ians.

Key Stakeholders need to adopt additional preventive measures for persons with IDD, in order to prevent their contract with such virus and promote healthy living.

ADDITIONAL CONSIDERATIONS:

These additional considerations are recommended for PwID as they themselves

(a) Couldn't gather and make use of information required for

preventing the contract with COVID-19

(b) Couldn't make access to public-care services, water and sanitation services.

(c) Couldn't avoid touching things which may be infected.

(d) Couldn't maintain wearing of mask for longer duration of time.

(e) Couldn't wash their hands properly and as per the guidelines issued by WHO and Indian Council of Medical Research (ICMR)

PwID may have other co-morbid conditions/ problems like motor deficits, epilepsy, allergies, gastroesophageal reflux disease (GERD), dysmenorrhea, seizures disorders, mental illness, oral health problems, constipation etc.

Appropriate actions need to be taken by various stakeholders in order to ensure proper service delivery and reducing barrier for PwID in service on which they rely.

RESULTS:

CONSIDERATIONS FOR STAKEHOLDERS

ACTIONS FOR FAMILY AND HOUSEHOLD OF PwID

Reducing Potential exposure to COVID-19.

- Family and household should follow WHO or country specific guidance on basic protection measures during COVID-19 outbreak. In India Arogya Setu app. Provides and updates regarding all kind of information related to COVID-19. If required, family must go for adaptations in accommodating their child with Intellectual disability for easy hand wash, using hand-basins, sinks etc.
- Family must ensure to not to take CwID to crowded places and avoiding physical contact of child with other persons.
- Essential items like Medication, Medical Supplies, Food, Sanitizers etc must be gathered by the family so as to avoid visiting crowded places time and again.
- Assistive devices/products, if used by the child must be disinfected frequently by the care-taker or family.

Keep an alternative Plan to continue the care of PwID.

- Families who rely on caregivers, they should increase the pool of caregivers if possible, whom they call upon if someone is unavailable some day or the other.
- Parent should try to involve themselves to the extent possible.
- Look forward to ensure the safety measures being adopted by the

caregiver while entering and leaving the house.

- If a caregiver is hired through an agency, look for contingency measures agency has to compensate the absentism of potential workforce.
- Identify relevant organization working in the field of Intellectual Disability in your area to call upon when you need any help.

Preparing household in case PwID got infected with COVID-19

- Family must ensure to call upon National COVID-19 helpline number and till the time must ensure to track the person and his previous history of contact or exposure.
- Don't panic at all.
- Isolate the person in separate room and apply face mask on his face of house properly cleaned and sanitized until the help arrives.
- Call nearby disability associated organization to ask for any such help required to manage the health needs of the person.
- Continuously monitor the persons from a safe distance and disseminate information clearly to the medical health team regarding Intellectual and associated health conditions including medication taken.

ACTIONS FOR GOVERNMENT

Ensuring Accessible Public Health Information and Communication

- Preparing "Easy Read" material in all languages to increase comprehension of the guidelines regarding COVID-19 for all parents.
- Using Inclusive images with brief captioning for easy understanding by Mild Intellectual Disabled individuals like Hand Washing, Social distancing, Wearing Mask etc.
- Instructing disability organizations to disseminate required information to PwID at their level.

Supporting PwID and their family:

- Pensions given to registered PwID can be enhanced to provide financial support to person and his family.
- Financial Compensation to families who need to stay home to take care of PwID or have to self-isolate themselves to avoid getting contract with COVID-19.
- Appropriate action on providing education to CwID during curfews or lockdowns and instructing teachers to help parents manage child behavior appropriately at home.
- Providing disability caregiver providers with free cost face masks, sanitizers, gloves and other safety equipments.
- Testing PwID and their caregivers free of cost for COVID-19.
- Allowing Special Educator and Parents to help PwID in cooperating Medical staff while sample collection or during treatment period (Considering the safety of assistant of PwID).
- Try to follow such diet which can boost the immunity of persons with intellectual disability affected.
- Allowing caregivers exemptions from curfews in order to maintain their continuity in providing service to PwID.
- Granting exemptions to PwID to move out of home for some time.
- Ensuring human right protection measures which should not be compromised in the light of emergency measures.

ACTIONS FOR HEALTH-CARE

Ensuring Accessible, Affordable and Inclusive Health Care Service

- Ensuring removal of Physical Barriers, Attitudinal Barrier and Financial Barrier at Health Care Service Centres
- Providing Home based consultation to PwID who couldn't reach the institution.
- Special Educators, Social Servant, Family and Caregivers consultation must be taken before quarantine PwID.
- Enhancing reach of family of PwID to the health care service for person through telehealth or video conferencing
- Involving Community based agencies in providing support to PwID.
- Ensuring accessible transport and working with communities and OPDs to avoid de-prioritizing to medical attention (UNICEF).

ACTIONS FOR EDUCATIONAL INSTITUTIONS

Ensuring Safety in Institutional residence/Hostels

- Cleaning, sanitizing the room properly along with changing the bedsheets, curtains frequently.
- Helping CwID in maintaining proper hygiene and cleaning washrooms, changing places properly.

- Ensuring safety of helper, if coming from outside the institution.
- Providing healthy diets to CwID and following eating habits guidelines given by ICMR or WHO to improve immune system.
- Following Social Distancing within the institution as well in the rooms by avoiding overcrowding of the rooms.
- Stocking essential items like food, medication, drinking water etc. in advance to avoid its shortage and continuation of care provided.
- Implement infection control measures within institutes like wearing masks, gloves, handwash etc.
- Avoiding pressurizing the parents to take their child from hostel in case essential supplies began to extinct.

Ensuring educational support to CwID through alternate mode

- Maintaining educational support to Mild Intellectually Disabled through online or telephonic mode.
- Follow-up with family of CwID regarding educational needs of child.
- Special educators must make use of Simulation teaching to disseminate educational services among CwID.
- Instructing and Assisting parents in planning and preparing educational material and program for their wards.
- Informing parents about simple and affordable home based activity to engage and maintain appropriate behavior among Children with Problematic behavior and ADD/ADHD children.
- Providing support to children with severe intellectual disability through online or telephonic mode by consulting and guiding the parents.

ACTION FOR ANGANWADI AND COMMUNITY WORKERS

- Ensuring follow-up with family of PwID regarding health state of person and intimating general guidelines for preventive measure of COVID-19.
- Exploring government policies and support to provide required financial and medical attention to PwID.
- Providing emotional and practical support to persons with Intellectual Disability, respecting social isolation restrictions that may be in place.
- Be cognisant while talking about COVID-19 to the PwID or to family and avoid increasing stress among them.
- Motivating family of infected PwID and helping them in managing stress.

DISCUSSION

People with ID are at greater risk of infection for a range of reasons that include physical health problems, social circumstances and limitations in understanding (Grier *et al.* 2020). Respiratory infections are the leading cause of death in people with ID (O'Leary *et al.* 2018) especially among people with Down syndrome (O'Leary *et al.* 2018). People with intellectual disabilities often utilize resources such as home health aides, day programmes, drop-in centres, family respite services and group homes. For health and safety reasons, many of these services are now unavailable or closed, increasing the responsibility of family members, affecting the routine of people with intellectual disabilities and significantly impacting their independence. Some people with intellectual disabilities are not able to quarantine alone or stay with their families due to their enhanced medical or behavioral needs. Remaining in group homes or similar long-term care facilities can allow people with intellectual disabilities access to the care they need, but may put them at a much greater risk of infection. Hence, it was concluded that although World Health Organization (WHO) has given a general consideration covering all disabilities under single roof regarding safeguarding People with Intellectual Disability in this time of pandemic by removing barriers and promoting inclusive approach which must be done by all the stakeholders, but there were some points which have special reference to Persons with Intellectual Disability and required to be mentioned specifically keeping in mind the severity and co-morbid condition of individual. As every child with intellectual disability is unique and have different condition all together. Hence the investigators have included all such required points along with WHO in this paper, to make it appropriate and relevance specifically for children and adolescent with Intellectual Disability and other developmental disabilities. This paper will also help various stakeholders to understand their role in this time of pandemic and the role they need to play in order to mitigate the impact of COVID-19 for Persons with Intellectual Disability. Additional consideration will equip stakeholders with all relevant and necessary precautions to be taken at this time. These considerations will also help in empowerment of PwID and their carers to face future outbreaks of such infections. (Courtenay, K., 2020).

REFERENCES

1. <http://www.pacificdisability.org/News/Disability-and-COVID-19.aspx>
2. <https://www.disabilitycoop.com/2020/06/08/people-with-developmental-disabilities-more-likely-to-die-from-covid-19/28434/>
3. <https://www.webmd.com/lung/news/20200608/intellectual-disability-raises-covid19-death-risk#1>
4. [https://www.unicef.org/disabilities/files/COVID-19 response considerations for people with disabilities 190320.pdf](https://www.unicef.org/disabilities/files/COVID-19%20response%20considerations%20for%20people%20with%20disabilities%20190320.pdf)
5. <https://www.weforum.org/agenda/2020/04/covid19-coronavirus-intellectual-disabilities-loneliness/>
6. <https://www.newindianexpress.com/lifestyle/health/2020/may/29/people-with-intellectual-disabilities-at-high-covid-19-death-risk-study-2149581.html>
7. Courtenay, K. and Perera, B., (2020) COVID-10 and people with Intellectual Disability: Impact of a pandemic, *International Journal of Psychological Medicine*, 1-6
8. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7287305/>
9. https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/covid-19-facultypsychid.pdf?sfvrsn=86f6a7da_