

COVID-19 - Impact on the Parents of Children with Special Needs

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ABSTRACT

Covid-19 has brought unprecedented challenges in India. People have developed stress, fear, and apprehensions about the corona virus. Lockdown has created many hurdles to all of us and mostly the impact is seen in the lifestyle of children with disabilities. Lockdown has disrupted the routine of school hours, therapeutic sessions, and educational interventions of our children with special needs (cwsn). Our cwsn who are children with intellectual disability, cerebral palsy, and autism were forced to stay at home. They had developed physical, emotional, and behavioral problems due to unavailability of center-based services and therapeutic interventions which is a dire necessity for them. The role of educational and training institutions, special schools had become more indispensable. The special educators and therapists such as speech therapists, occupational therapists, physiotherapists, and psychologists had started rendering their devoted and unconditional online services for cwsn. The present paper focuses on the impact of Covid 19, on the parents of cwsn and their implementation of therapeutic services to them at home. A questionnaire was developed by the researcher to find out the Impact of COVID 19 during lockdown on the parents of the children with special needs. Around 178 parents responded to the questionnaire on the Google form. The results found are very practical, effective and remarkable as the entire family was involved in training the cwsn at home with utmost care love and affection.

Key words; Corona Virus, Lockdown, Children with special Needs, Parents, Therapists, Special educators.

INTRODUCTION

Covid-19 has brought unprecedented challenges in India. People have developed stress, fear, and apprehensions about the corona virus. Lockdown has created many hurdles to all of us and mostly the impact is seen in the lifestyle of children with disabilities. Lockdown has disrupted the routine of school hours, therapeutic sessions, and educational interventions of our children with special needs (CWSN).

Our cwsn who are children with intellectual disability, cerebral palsy, and autism are forced to stay at home. They have developed physical, emotional, and behavioral problems due to unavailability of center-based services and therapeutic interventions which is a dire necessity for them. The role of educational and training institutions, special schools now have become more indispensable.

The special educators and therapists such as speech therapists, occupational therapists, physiotherapists, and psychologists had started rendering their devoted and unconditional online services for cwsn. Special educators and therapists are creating activity-based worksheets, developing videos depicting learning of various skills, and also the explanation of the skills through audio mode. These strategies have been implemented by special teachers and therapists to train the parents of our cwsn so that they can, in turn, train them at home efficiently.

The home of the special children has become a special school and parents, siblings and other family members have become special teachers to carry out their duties judiciously by rendering training to them.

REVIEW OF LITERATURE

Rakab et.al; (2022) The purpose of this study was to investigate the impact of the COVID-19 pandemic on the quality of life of families of children with disabilities and the mediating roles of perceived social support, perceived parental self-efficacy, psychological health, psychological resilience, and perceived family burden on this

relationship. A correlational survey design was used to collect data from 824 parents of children with disabilities in Turkey. Results indicated that COVID-19 had a significant total effect on family quality of life and perceived social support, parental self-efficacy and psychological resilience had a mediating role on the relationship between impact of the COVID-19 pandemic and family quality of life. Perceived social support was found to be the strongest mediator of the relationship between the impact of COVID-19 and the family quality of life, while perceived family burden did not have a statistically significant association with these variables. COVID-19 has resulted in disruption of special education and rehabilitation services for children with disabilities and their families. Changes in daily routines have brought up additional responsibilities to parents of children with disabilities. These additional responsibilities may adversely affect and increase the burden and stress families of children with disabilities experience. The high levels of stress in families negatively affect the welfare and quality of life and result in decreased parental attention to support their children.

Zebracki (2022), found that during forced homeschooling, parents' increased roles as their children's teachers provided a closer insight into what children face daily and which areas may be more challenging than others. This led to opportunities to not only teach their children academic skills, but also coping strategies in how to manage frustration and stressors. This new perspective may also improve the partnership between parents and schools to promote their children's successes. Moreover, with the growth of video conferencing, parents potentially have improved access to communicate directly and more frequently with teachers. With suspension of competitive sports and extracurricular activities, unstructured and nature play increased. Nature play has been associated with positive outcomes in physical, cognitive (creativity, imagination), and social and emotional health in children.³ Simplifying children's schedules, rather than overbooking them, may help reduce stress as well as providing time in which to try new activities and reprioritize interests and goals. Puzzles, in particular, became sought-out activities. Unstructured play helped families rediscover the joy of shared family recreation. The emotional toll of the pandemic affected both parents and children. With its undiscerning impact on society, there has also been an increase in open discussion regarding mental health concerns. This renewed focus has the potential to bring needed treatment to children and their families. Schools, for example, are recognizing the need for routine screens and check-in regarding their students' mental health and are integrating social and emotional learning programs into curriculums

Mathilde (2021), found that in the context of the pandemic, parents and caregivers of children with disabilities or complex chronic disorders faced unprecedented, at times insurmountable dilemmas. Schools and residential care facilities closed their doors; non-acute management was severely disrupted. Parents and carers had to decide on their own whether to take their children out of care and return them to the family home, or leave them in the usual living environment, where visits and other social contacts were drastically reduced or prohibited. In some instances, support for home care provision stopped and many aspects of daily life were put on hold for extended periods, with no promise of normalization. Restrictions on shopping, e.g. single, unaccompanied person, added to the multiplicity of challenges. These measures were rightly based on expert evidence, and they are indeed common-sense measures, but their application may have proved unmanageable for the families of disabled children. Parents report a latent sense of guilt about the difficulty of making choices and their inability to take on all these new roles. The pandemic has exacerbated and highlighted the different realities and inequalities that exist within society. Coherent assessments and lessons for the future are now beginning to take shape, but slowly.

Saeed et al.;(2020) studied the effect of COVID-19 on parents of children with special needs. For this study, a questionnaire with a 5-point Likert scale was developed by a team of psychologists to assess and evaluate the effect of COVID-19 on parents of children with special needs. A total of 44 participants had responded to the questionnaire. The parents of children with special needs invariably experienced significant levels of stress during COVID-19. The results also indicated that the parents were engaged in activities as most effective strategy to combat the stress faced during Covid 19.

METHODOLOGY

The present paper focuses on the effective initiatives in the conduction of online training to our cwsn during this lockdown period by our team of special educators and therapists of Aakanksha Lions Institute of Learning and Empowerment (ALILE) Raipur, Chhattisgarh. A questionnaire was developed by the researcher to find out the impact of COVID 19 during lockdown on the parents of the children with special needs.

SAMPLE

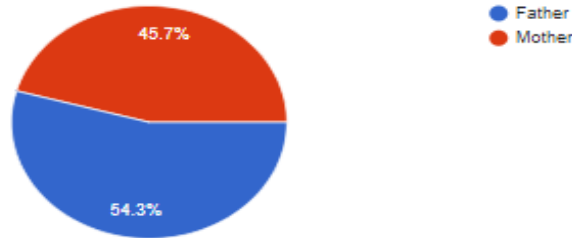
A total of 178 Parents of children with special needs had responded to the questionnaire. The questionnaire consist of 40 questions and 5 probable answers corresponding to the questions. The demographic details of parents was gathered and parents were informed that the information gathered is to help for betterment and guidance to the cwsn. The names of parents and their wards is kept confidential.

PROCEDURE

The parents and other family members were asked to answer the questionnaire sent on the Google Form.

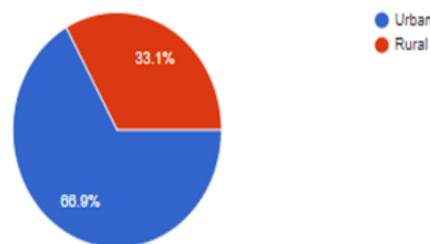
RESULT AND DISCUSSION

The results of the present study is depicted below.



The pie graph represents the participants ie., 45.7% were mothers and 54.3% were mothers. This rise in the numbers of Fathers participation is due to the Lockdown and all the fathers were at home.

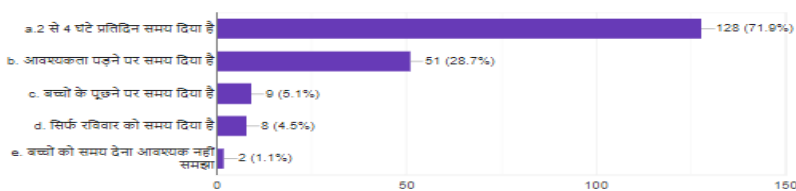
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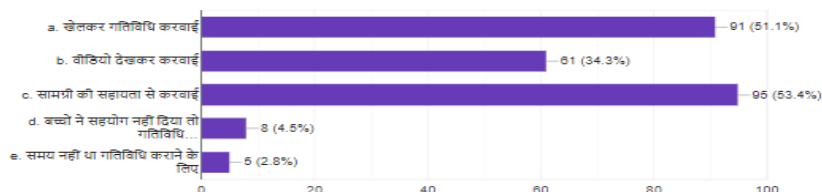
The information from the pie graph depicts that most of the participants were from Urban areas. The details of the present survey research is given in graphical representation which delineates the highest and lowest percentages of the answers to the respective questions.

Graph no 1.

1. आपने अपने विशेष बच्चों को कोविड-19 लॉकडाउन के समय घर पर -
178 responses



4. आपने अपने विशेष बच्चों को गतिविधियां किस तरह कराएं-
178 responses



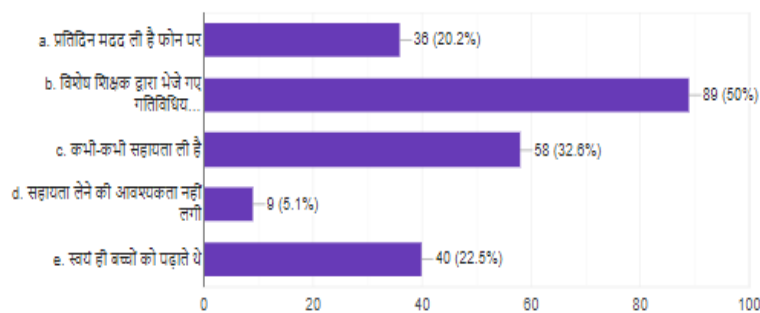
The result on the question 1, as to how much time did the parents devoted to teach their cwsn at home during lockdown revealed that maximum 71% parents did spent time to teach their cwsn at home during lockdown where as 2.1% expressed that teaching cwsn at home was not required. This positive result indicates that , there is dire need to give time to teach our cwsn at home too as they tend to forget easily. .There are many modes of teaching techniques by which the parents were taught to in turn teach their cwsn at home. This might be the reason , that a positive result of parents expressed to render training their cwsn at home.

For question 4, the 95% parents responded that they utilised the resource materials available at home as teaching learning material (TLM) for teaching their cwsn at home, and 5% parents reported that due to scarcity of time they could not teach their cwsn at home with ant TLM .

Graph No. 2

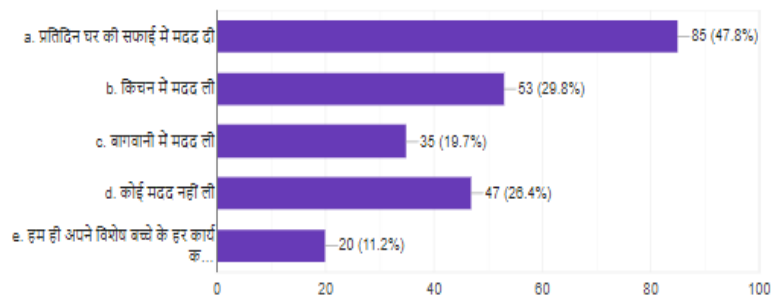
5. आपने विशेष बच्चों को पढ़ाने के लिए विशेष शिक्षकों से सहायता ली है-

178 responses



7. आपने अपने विशेष बच्चे से घर के कार्यों में-

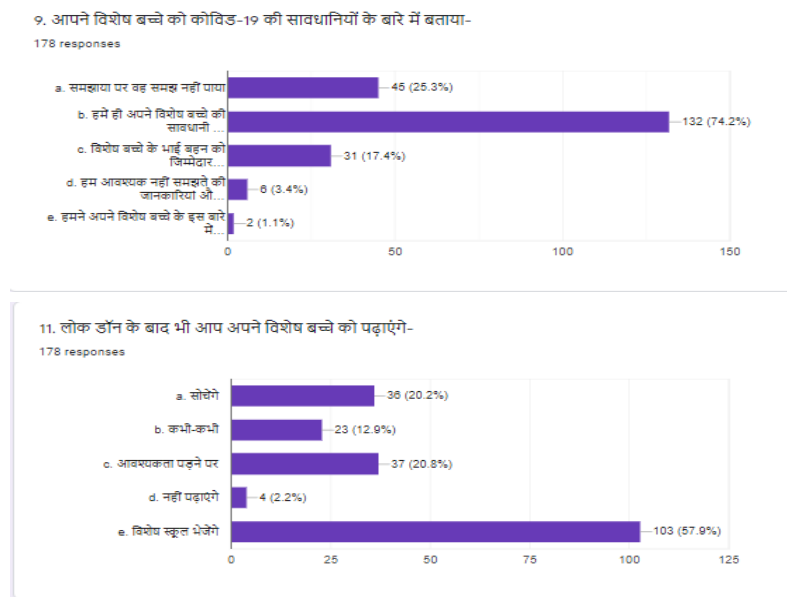
178 responses



For the question 5, which states that, did the parents take the necessary help from the special educators to teach their cwsn at home during lockdown . The result for this question revealed that 50% of parents reported that they took the help of special educators by utilising the activities sent to them by these special educators through whatsapp images and videos . These activities were very useful for the parents in teaching the cwsn at home , whereas 5.1% of parents reported that they did not feel the necessity of taking support from the special educators . The parents become special teachers as their role was very effectively utilised by parents and very positive result was achieved. Hence involvement of special teachers was very effective.

For question 7, 47% of the parents responded that involved their cwsn in helping the parents at home for simple house hold chores where as 11% reported that they did the all the work of their cwsn. The positive note of this result shows that taking the help of cwsn at home had double folded advantage. First they followed the instructions given to them and secondly they learnt the way how to perform the chores which are useful for them.

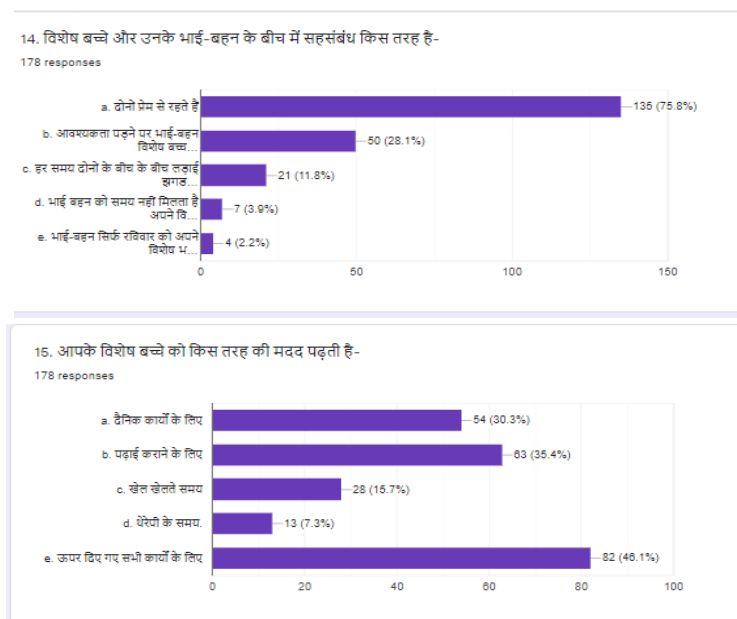
Graph No. 3



For the question 9, which states that, did the parents informed their cwsn about the guidelines of Covid 19 for which around 72% of parents did informed and also made them follow the guidelines accordingly but 1.1% of parents did not feel the necessity of informing their cwsn about Covid 19 guidelines. By doing so, the parents developed sensitisation and awareness on COVID 19 very important. With this information, although most of our cwsn do not comprehend the cause and effect of this pandemic, but with constant gentle reminders our cwsn also cooperated and followed the guidelines as required.

The question no 11, directly related to the continuation of sending cwsn to special schools after the lockdown, for which 67% parents agreed to do so but 2.2% parents were still hesitant and unwilling to send. For this basic reason, the children were being taught at home regularly through online mode, but parents will be counselled to send cwsn to special schools as it also becomes essential to render school environment, peer group interaction, teacher-student bonding and above all the therapies for cwsn.

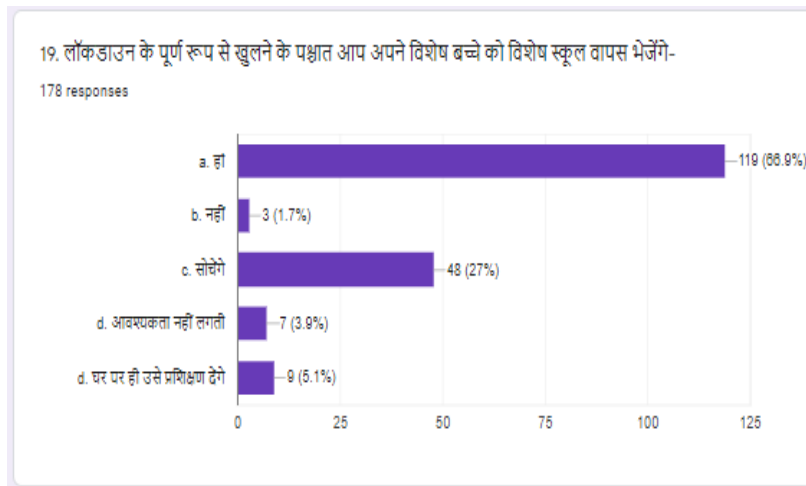
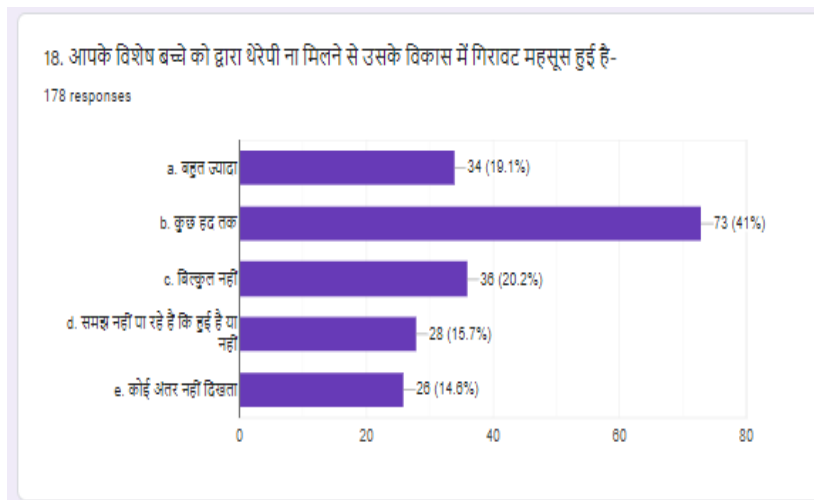
Graph No. 4



The question 14, is related to the sibling relationship and bondage with regular sibling and cwsn . The results indicated that 75% of parents reported that there was a strong sibling bondage and relationship established during this lockdown between regular siblings and cwsn. The siblings did most of the time actually spent quality and quantity time with the cwsn by teaching them the concepts, playing with them and enjoying the entertainment time with the cwsn. But 2.2% of parents reported that although their regular children did spend time with cwsn but only on Sundays. This positive result indicates the Sibling Bondage and relationship as important as parent child bondage. The future care takers of cwsn are the siblings. Siblings involvement and responsibility is very effective on the cwsn development.

The result on question no 15 by the parents was that 46% of parents rated that there were helping and guiding their cwsn during lockdown for self help skills, during teaching academics and concepts, and during therapeutics, but 13 % of parents reported that they helped or supported their cwsn only during therapeutics.

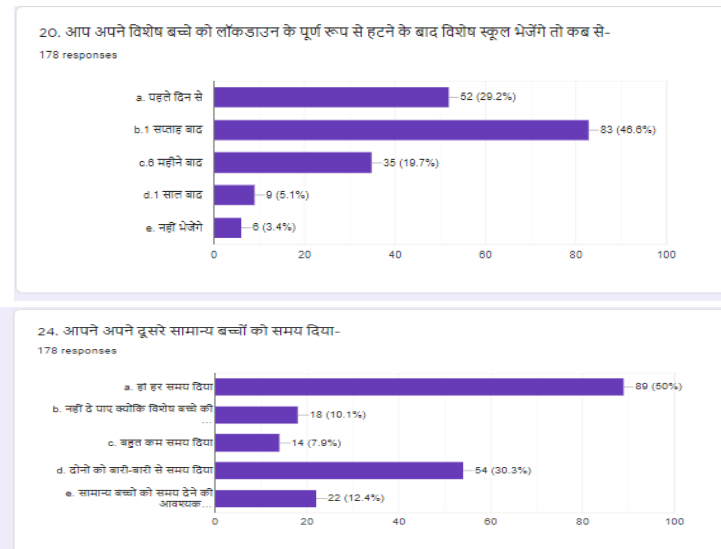
Graph No.5



The result on the question 18, revealed that 41% parents reported drastic deterioration in the behaviour of cwsn due to non availability of services where as 14% of parents did not observe any difference in the behaviours of their cwsn during lockdown. During lockdown , the impact on the decrease in the progress of cwsn in all areas is very alarming. Hence parents were regularly contacted and training given online to cater to the needs of cwsn in crises situations.

For question 19, 66% parents responded that they send their cwsn to special school after the lockdown but 1% of parents said no. The impact of special school has its positive concerns as the overall development of cwsn is more challenging after the post covid 19, new normal concept.

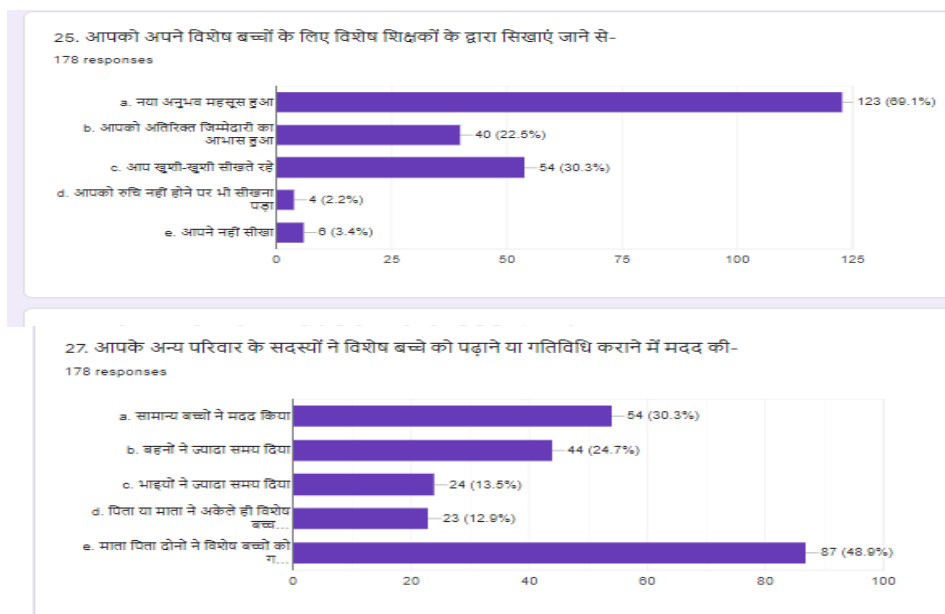
Graph No.6



The result on question 20, revealed that 46.6% parents are willing to send their cwsn immediately after one week of opening of lockdown, but 3.4% of parents did not want to send to special school. The fear gripped by parents regarding resuming the school post covid 19 has to be taken care cautiously. The parents were counselled regarding this sensitive issue efficiently.

The result of question 24 revealed that 50% of parents gave quality and quantity time to their other normal children during lockdown, when they had also been taking care of cwsn at home. Where as only 7.9% parents reported that they gave partial time and literally very less time to their so called typical children. Parents are mostly impartial and spent time with children for both normal and cwsn. Parental concerns, parenting styles, and parenting skills are need of the hour. Parents require proper guidance and counselling to take care of these issues.

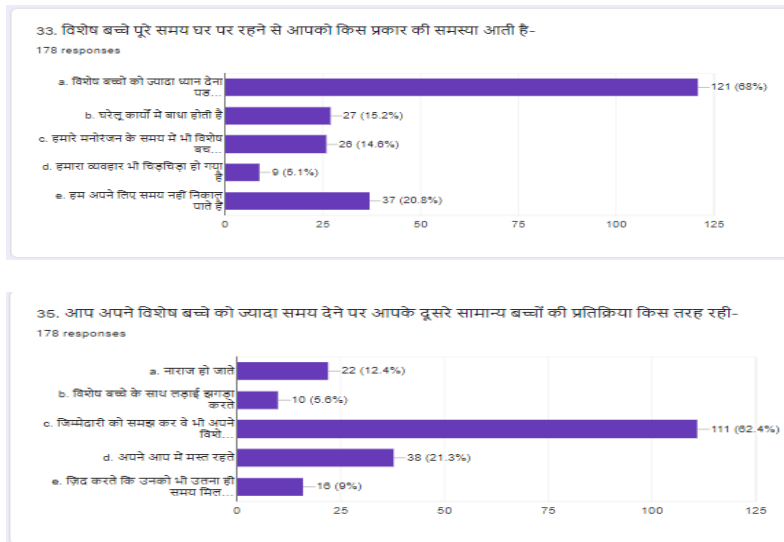
Graph No.7



The result on question 26, revealed that 74.2% parents had rendered training to their cwsn on their own experiences and 1.7% of parents did not do. This is an eye opener to all parents, if Covid 19 is taken in a positive manner with respect to our cwsn. Fathers gave ample time to the children. Family unity and fun time was experienced. Secondly parents enjoyed learning a new role of teaching their cwsn as a substitute special educator.

The result of question 27 revealed that 48 % mostly fathers and mothers together as one unit were the key persons rendering training to cwsn at home during lockdown, but 12% of parents reported that either mother or father had been taking care of their cwsn during lockdown. The whole family was a single unit sharing the responsibility and taking turns to teach the cwsn in a play way manner.

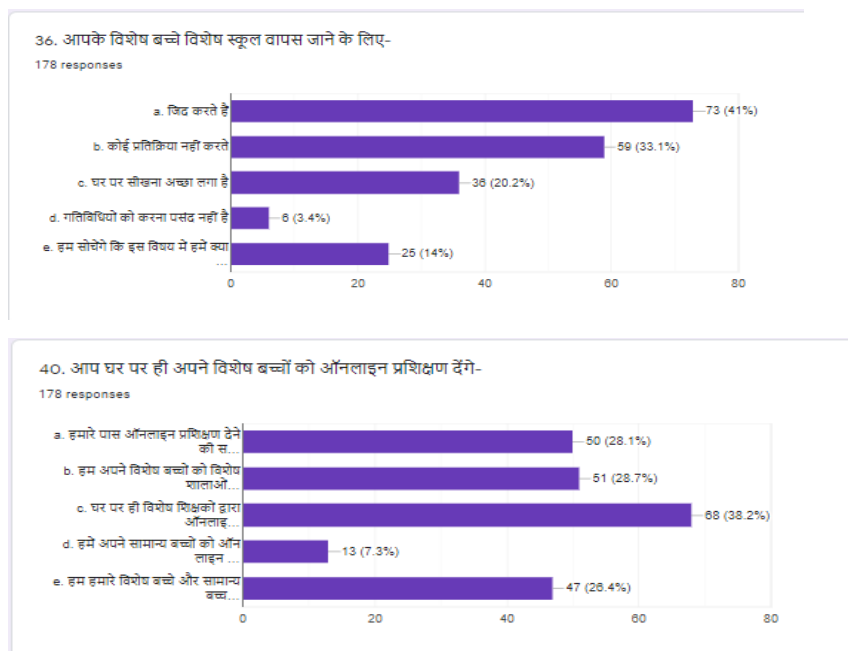
Graph No.8



The result of question 33 revealed that 68 % of parents reported that they had to give maximum time in taking care of cwsn during lockdown. While 5.1% of parents revealed that they had become repulsive and aggressive too by taking care of their cwsn regularly. The repulse behaviours of parents needed to be taken care by counselling and positive reinforcement approaches.

The result of question 35 revealed that 62 % of parents reported the family members and especially the siblings of cwsn had cooperated during lockdown and helped parents in taking care rather than feeling neglected and partial towards their cwsn and their parents. The siblings did not complain about any such negative feelings towards their cwsn siblings. The behaviour of parents was taken positively by the siblings and they in turn became more involving, more caring and loving towards their brothers or sisters with special needs.

Graph no 9.



The result of question 36 revealed that 41 % of parents reported that the cwsn insisted on going to special school during the lockdown period, the cwsn used to throw temper tantrums and created havoc to go to special school, where as 3% of the parents revealed that the cwsn did not like to perform the activities sent to them by the special educators. Children get used to a regular routine at home and at school. During Lockdown, this routine was disturbed. At this time, parents were advised to create school like environment in a simulated manner at home with the routine of school followed at home. This gesture is important for gaining attention and cooperation of cwsn at home too.

The result of question 40 revealed that 38.2 % of parents reported that the parents were willing to continue the online way of teaching their cwsn at home with the help of special educators rather than sending them to special school. The fear of the corona has left an impeccable negative remark on the parents and they were scared of their cwsn getting corona . Hence such a result was predicted. Parents are very willingly imparting training with the activities provided by the special teachers at home. But they have to take care of their other normal children too simultaneously, which is only possible by training the parents the art of sharing responsibilities and role playing techniques.

CONCLUSION

The survey study on the impact of Covid 19 , on the parents of children with disabilities was conducted to find out both the positive and negative aspects of Covid 19 . During the lockdown period , the whole scenario of regular services to the cwsn was hampered and disturbed. This lockdown was very scary, sudden and perplexed too. The parents were unprepared for this kind of reactions which were devastating and detrimental for the overall development of cwsn. But a sigh of solace was the prompt and regular support from the special educators who were constantly in touch with the parents and started training them on line depending on the needs of the children. The training although covered adaptive skills, academic skills, speech therapy, physiotherapy , occupational therapy and psychological guidance and counselling took care of boosting the morale and motivating the parents to become special educators of their cwsn at home. The study concludes that parents took active participation in teaching their cwsn at home by in turn getting trained by the therapists and special educators. The response of the parents was positive and remarkable . Fathers too played a vital role in taking care of cwsn during this time.

LIMITATIONS

There could have been a study survey on the parents of cwsn depending on the types of disabilities i.e; for cwsn with intellectual disability, autism, cerebral palsy etc.

RECOMMENDATIONS

1. Home Based Parent training on taking care of cwsn
2. Training of handling cwsn in emergency situations to parents, special educators and care takers .
3. Training to siblings on taking care of their siblings with disability.

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