



Role of NGOs in Care of Children with Intellectual Developmental Disorder (IDD)

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ABSTRACT

Caring a child with Intellectual Developmental Disorder (IDD) is not an easy task. But this challenging service is providing by many NGOs with a great enthusiasm. The service they contribute to the upliftment of IDD children reduces the challenges that parents carry in their life while they upbringing their child with IDD. This paper highlights the role that NGOs play in the developmental process of children with IDD and their proper care. This is a descriptive study which describes the role and challenges that NGOs pursue in their service while they provide care to child with IDD. The researcher applied a quantitative methodology in the study. The study was based on the data collected from eight NGOs working in the field of IDD in the district of Kottayam, Kerala and Satara, Maharashtra. Researcher used a semi-structured interview schedule for the data collection. Major findings of the study were, the highest number of children with IDD associated to the NGOs were moderate, mild, severe and profound simultaneously. All NGOs were running special schools and rendered services to children affected with autism, down syndrome, cerebral palsy and multiple forms of disability under one umbrella term Intellectual Developmental Disorder (IDD). Financial crisis was the major challenge that NGOs were undergoing. The risk factors that they observed in study were behavioral problems, hyper activity, epileptic conditions, managing according to the regulations, parental demands, non-supportive and not sanctioning fully aided post to the NGOs by government.

Introduction

NGOs are providing services in many sectors and function as a helping hand for people and agent or mediator between government and people. They are working in an organizational setup with special charism and focus. Children with Intellectual Developmental Disorder (IDD) is a population which needs special attention, care and protection. Caring and support that NGOs provide through therapy, special education, vocational training and other activities enriches children with IDD in the developmental process. Government provides caring of this population with different policies and acts like National Trust Act, RPWD Act, scholarships and pensions etc. NGOs stands for availing these benefits to them. NGOs functions as a formal caregiver to them. This study focusses on the role that NGOs play in the developmental process and caring of children with IDD. The service they provide reduce the burden of parents of IDD children.

Objectives of the study:

1. To describe the services and role that NGOs provide to IDD children and evaluate its benefits
2. To analyze the challenges that NGOs facing while providing the services to IDD children.

Research Design

The study was based on the data collected from eight NGOs working in the field of IDD in the district of Kottayam, Kerala and Satara, Maharashtra. Researcher used a semi-structured interview schedule for the data collection. All the eight NGOs were running special schools for the development of children with intellectual disability. The study was looking at the role of NGOs and their challenges while they execute their services in different mode. It points out the areas of services and the development of the child that comes under because of the services provided by the NGO as a second parent to the child with Intellectual disability. The support they get in their organization from government and support received by parents from government were also discussed in the study.

Review of Literature

There are many studies that emphasise the role of NGOs and parents in caregiving role of child with Intellectual Developmental Disorder (IDD). Here I am going to narrate certain studies and their finding related to this topic for the study. and health impact, financial impact and social impact. (Adithyan, Sivakami, & Jacob, 2017).

Olagoke Akintola's qualitative study on "Perceptions of rewards among volunteer caregivers of people living with AIDS working in faith-based organizations in South Africa" shed light on caregivers and NGOs volunteer service roles. The study highlights the finding that volunteer caregivers' subjective and objective burden may be reduced by the rewards and these rewards play a vital role in encouraging volunteer interest in working with care organizations (Akintola, 2010). "Challenges of caregivers providing care to children with disabilities at non-governmental organisations in Tshwane townships, South Africa" by narrated certain insights on caregivers' challenges. The study came up with the result under six major themes like initial impressions, rendering care, stress, lack of outside support, coping and poor community recognition. The initial reaction of caregiver was shock, sadness and fear. The unpreparedness of them created this kind of reaction. Caregivers' challenges while render care to children were related to bathing, dressing, feeding, positioning and stimulation of their care recipient. They experienced stress because they were not equipped with the skills and knowledge to render care. They were in need of external support from government and professional services. They faced difficulty in coping with challenges and some adopted maladaptive coping strategies like taking pills and consuming alcohol to cope up with stressors. Community was not understanding the need of service and they were stigmatized. They suggested in their study that understanding many challenges of caregivers is crucial for developing empowerment programmes for them and that kind of empowerment of caregivers will ensure comprehensive, optimal care and quality of life (Tayob & Risenga, 2022).

Social support of caregivers of children with intellectual disabilities in India and South Africa described and compared by Shakila Dada, Kirsty Bastable & Santoshi Halder by using the Family Support Survey (FSS). There was a linkage between caregivers' capacity to support children's participation and to the social support that they receive as caregivers. The study came up with the result that perceived social support of caregivers differs between countries and is associated with their child's participation (Dada, Bastable, & Halder, 2020).

Methodology

This is a descriptive study which describes the role and challenges that NGOs pursue in their service while they provide care to child with IDD. The researcher applied a quantitative methodology in the study. The study was based on the data collected from eight NGOs working in the field of IDD in the district of Kottayam, Kerala and Satara, Maharashtra. Researcher used a semi-structured interview schedule for the data collection. Interview schedule covered facts, opinions and views of the responsible persons of different NGOs. The study evaluated different services providing to children with IDD by NGOs.

Data Analysis and discussion

The data is analyzed with statistical tools. Quantitative data entered in SPSS and interpreted with statistical tests like correlation, descriptive statistics, mean, standard deviation and other statistical tools. Open-ended questions analyzed thematically in the study. There were three sets of semi-structured interview schedule and each one entered separately in SPSS and evaluated.

NGO's Profile

The researcher interviewed three sets of people with a semi-structured interview-schedule. He collected data from 5 NGOs in which one from Maharashtra and four from Kerala from the districts of Satara and Kottayam. Out of this five NGOs, four are running by religious institutions and one is managed by private association. All the NGOs are registered under Society Act or Trust Act. These NGOs are established from 1989 to 2002. Each NGO has its own moto and focus of intervention even though all of them provide service to similar categories of children. The moto of these NGOs was: love, care and service; moving towards with dignity; total development; total development of differently abled and a candle loses nothing its light by lighting another candle. Majority of respondents who represented their NGO in this study were principals and in one NGO, the Co-Ordinator of the NGO participated in this study. Some of the NGOs represented in this study were situated in rural and others in urban areas.

All the NGOs are getting some sort of grant from either central or state governments. But all the NGOs are receiving donation to meet its expenses and majority of them have 12 A, newly 10 A and 80G, newly, 10 AC tax exemption. NGOs are paying salary for employers with partial help from government except one NGO in this study. The staff is getting salary from government in one NGO. Monthly expense of these NGOs varies from 2 lakhs to 5 lakhs according to its strength and activities. No one have any financial loan or liability while running their NGOs. All the NGOs are running by their own building and not in any rented or leased building. Two NGOs were providing both residential and non-residential service whereas others were giving only non-residential services.

NGO's Services

The beneficiaries of the service rendered by these NGOs varies from 44 to 230 children out of which 255 boys and 205 girls. The ratio of boys is higher than girls by almost 20%. The category wise children with IDD are: mild-132, moderate-153, severe-104 and profound-68. The majority of beneficiaries were children with moderate IDD and children with mild and severe were also somehow near to the percentage to moderate IDD. Whereas profound category children were less in number. One reason for that may be, majority of NGOs were mainly concentrating on special education and in many cases

severe and profound category children were having multiple forms of disabilities and therefore educating them instead of supporting them with care and protection was not an easy task. The major support that NGOs provide for them was therapeutic interventions for life support and ADL (Activities of Daily Living) training. The internal consistency of different categories in NGO was also significant. In all the NGOs moderate children were high in number and mild, severe and profound simultaneously. In one NGO, there were no severe categories of children but the number of profound children admitted at their center was high in number in comparison with other NGOs. There were children affected with autistic, Down syndrome, cerebral palsy and multiple forms of disability. Majority of NGOs who were rendering services to IDD children encompasses services to these categories of children. There were only one NGO having a full-time social worker.

Statistical Analysis of NGO's service

There was a positive significant correlation between number of children and number of staffs in different degrees. Number of children with number of special educators' ($r = .997^{**}$, $P = .000 < .05$) care takers ($r = .989^{**}$, $P = .001 < .05$), social workers ($r = .988^{**}$, $P = .002 < .05$) and drivers ($r = .988^{**}$, $P = .002 < .05$) had strong positive correlation. It means that number of staff-special educators, care takers, social workers and drivers increase according to the number of children. We could see a strong positive relationship with this staff pattern. There is a moderate correlation between number of children and number of staff like physio-therapist ($r = .322$, $P = .597 > .05$), speech therapist ($r = .413$, $P = .489 > .05$), psychologist ($r = .057$, $P = .927 > .05$), doctors ($r = .538$, $P = .350 > .05$), staff nurse ($r = .336$, $P = .580 > .05$), musician ($r = .637$, $P = .248 > .05$) and art and craft teacher ($r = .637$, $P = .248 > .05$) but there is no significance or it is not a significant relationship. We could see a perfect significant positive correlation between number of musician and number of artist ($r = 1.000^{**}$, $P = .000 < .05$). There was strong significant correlation between number of care takers and number of drivers ($r = .966^{**}$, $P = .008 < .05$), number of special educators and number of social workers ($r = .991^{**}$, $P = .001 < .05$). There was weak and moderate negative correlation between number of staff doctors with number of psychologist ($r = -.218$, $P = .724 > .05$) and speech therapist ($r = -.327$, $P = .591 > .05$) but there it was not a significant relationship. A negative weak, moderate and strong correlation have been observed between number of staff nurse with number of psychologist ($r = -.802$, $P = .103 > .05$), physio therapist ($r = -.250$, $P = .685 > .05$) and speech therapist ($r = -.535$, $P = .353 > .05$) but there was no significance.

Class rooms, staff rooms, guest room, dispensary, school bus, ramp/lift, disabled friendly toilets, indoor games, playground, speech therapy unit, visitors room and office were the facilities providing by all the NGOs included in this study. Dinig hall, kitchen, recreation hall, computer lab, physio therapy unit, sensory garden and play equipment were the facilities providing by four NGOs out of five NGOs participated in this study. There were three NGOs providing smart class facility and two NGOs equipped workshop facility. One NGO was providing other facilities like swimming pool and occupational therapy. It sheds light to the required to NGOs while they provide service to children with IDD.

NGOs representatives shared motivational factors behind this noble service. One respondent mentioned that their desire to lead these children to an independent life motivates them to do this service. Whereas other one shared that, love and passion for this profession motivates them to do this service. "It is the charism of our congregation and it motivates us to do this service", one respondent replied. Service for humanity motivated one NGO to do this service. Financial crisis was the major challenges expressed by all the five NGOs. Behavioral problems, hyper activity, epileptic conditions, managing according to the regulations, non-supportive and not sanctioning fully aided post to the NGOs by government and challenging behavior of children were the risk factors that observed in taking care of IDD children.

The NGOs were facilitating online classes, counseling, home based assignment and WhatsApp group interactions during covid-19 times. The positive aspect of this online service noted by one NGO representative was one to one attention to the child along with their parents. One respondent mentioned that around 70 to 80% children attended online classes. Respondents of the study expressed that government was not strongly supporting to the NGOs and someone observed that there were corruption and high demands from government officers and the department. Other observation was even though they were not supporting they were not doing any harm to the running of NGOs.

There were two NGO placed a full-time social worker. They have entrusted the duties of parental counseling, office works, documentations, coordinate the link between government services and fund-raising responsibilities to that social worker. In their opinion, social worker can intervene in care giving process through identification of children and encourage parents for special education and training, avail CSR funds and link with government schemes and policies. One respondent said that they require a male social worker but the problem was that they were not able to pay for them. It is relevant observation that since all NGOs are facing economical crisis in running these NGOs. "A social worker could extent service by providing parents' guidance, home visit, personal counseling etc.", one respondent replied to the researcher. One respondent shared that government is not sanctioning this post. All the NGOs are connected with certain national level, state level associations or organizations.

Areas of improvement on Child			
Sr. No	Areas	Frequency	Percentage
1	Health	13	93 %
2	Education	7	50 %
3	Skills	10	70 %
4	Social Interaction	7	50 %
5	ADL	13	93 %
6	Writing	7	50 %
7	Reading	5	36%
8	Social	8	65 %
9	Arithmetic	1	7 %
10	Group Play	8	57 %
11	Computer	2	14 %

The major areas of improvement observed in the study were health and ADL. Improvement in academic skills was less especially in reading and arithmetic. Social skills were also improved remarkably. Parents of the study evaluated NGO's service as excellent (78%) and very good (22%).

Major findings of the study

- Majority of NGOs who are working in the field of children with intellectual disability run are by religious organizations in Kerala
- Parents were getting scholarship and pension amount for their child with ID from state and central government. Financial support that NGO received from government was minimal. State government was not considering special educators with the pay scale of normal school teachers and many of the NGOs were running with the donations they were collecting through different means.
- The ratio of boys was higher than girls by almost 20% in NGO
- Children with moderate IDD and mild IDD were higher in whereas profound category children were less in number. One reason for that may be, majority of NGOs were mainly concentrating on special education and in many cases severe and profound category children were having multiple forms of disabilities and therefore educating them instead of supporting them with care and protection was not an easy task. The major support that NGOs provide for them was therapeutic interventions for life support and ADL (Activities of Daily Living) training. The internal consistency of different categories in NGO was also significant. In all the NGOs moderate children were high in number and mild, severe and profound simultaneously.
- All the schools were rendering services to children affected with autism, down syndrome, cerebral palsy and multiple forms of disability under one umbrella term Intellectual Developmental Disorder (IDD).
- The major challenge that NGOs were undergoing was financial crisis was. The risk factors that they observed in study were behavioral problems, hyper activity, epileptic conditions, managing according to the regulations, parental demands, non-supportive and not sanctioning fully aided post to the NGOs by government and challenging behavior of children IDD children.
- The NGOs provided online classes, counseling, home based assignment and WhatsApp group interactions during covid-19 times. The positive aspect of this online service noted by one NGO representative was one to one attention to the child along with their parents.

Limitations

The study is limited to a small sample size but it covers a quantitative data and analysis with open ended questions. The study is also limited to two districts of Kerala and Maharashtra.

Conclusion

Since the study was based on a limited data, its vision was also little narrow downed. So, it has a weightage problem to affirm major challenges described in this study. But it shed light to the different aspects of care giving role of both formal and informal caregivers and it also addressed different requirement and services that can be contributed by NGOs in service to children with IDD. It opened up many challenging roles that NGOs and parents undertaking through their noble service to the child with IDD.

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