

# COMMUNITY INVOLVEMENT IN THE LIVES OF INDIVIDUALS WITH DISABILITIES LEADS TO SOCIAL CHANGE

## Abstract

Change is a fundamental phenomenon of the universe. Change is happening all over the globe no element of this world is untouched with the concept of change. Our very environment where we are living is going through changes every other day. Community in which we live also go through various patterns of changes which leads to social change. Positive involvement of individuals with Disabilities is only possible with full contribution of community members both acquired their positions at elite class and also the involvement of a member or group of community who belongs to low wage group. To make a strong foundation every small contribution counts. Every small contribution has a power to change a nation and further changing the whole world. This chapter mainly focuses on the positive involvement of community in various life aspects of individuals having disabilities and how these can in turn result in bring about social change in a society where we are living.

**Key words:** Community, children with disabilities, involvement, Social change

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## I. INTRODUCTION

**“Alone, we can do so little; together, we can do so much” – Helen Keller**

**‘It takes a whole village to raise a child’** is a proverb that says that for children to experience and grow in a safe and healthy environment, an entire community of people must provide for and engage positively with children. These lines truly fit in when we talk about role of community in development of a human resource. In Indian culture community can be called as our second family. Our Social institutions have a very strong influence in our society. These Institutions play a key role in framing social policies for the betterment of the community as a whole. An active community leads to rapid social change, this also result in providing positive benefits to the society where we live both internally as well as externally.

When we talk about Social change it is a word that is used to show the changes that takes place in human interactions and interconnections with each other. Society is a network of social relationships which we form with each other. For instance, we make interconnections with each other on coming together at a common platform and hence social change means change in the system of social relationships.

According to International Encyclopedia social change means any modifications in the social structures where we are living or in other words it can be said changing the way one interact in a society. When we talk about community as have already mentioned an active community and that to a community which is ready to contribute to make difference in a world will definitely have a capacity to bring in a social change. To bring in social change it is also important to involve each and every individual who is the part of a community to feel included. When we talk about India which is often called as land of diversity. Where no event is complete without the integration and involvement of various communities together. In such a country community role to bring in social change become even more big and vast. From organizing a blood donation camp to food distribution drives everywhere one can see involvement of people belonging from a specific community or group of people belonging to different communities.

When we talk about bringing and involvement of each and every member of the community together it means no one is left behind form being involved in the process of social change. One of the most marginalized section of our society or community are children with special needs or in other words we call them Individuals with disabilities. They are facing what we call as social exclusion from the past times. Social exclusion faced by these individuals generally hinders the path of social change and full community involvement. Milner et. al. (2004) talked about Social exclusion and how it impacts people’s personal welfare and full participation in society in multiple ways. It can be improved at both personal and social levels personally and socially which can include accessibility to the social webs within different communities that support integration and building up of connection with others, so that everyone who is the a part of a community is able to access to its services and stimulations that will in result help in supporting in providing a fulfilling life, and the social and financial awards that is followed by employment and education.

Positive involvement of community in the lives of children with disabilities can change their very pattern of life. When community will show interest in the lives of these individuals things which they feel challenging can become opportunities for many of them.

There positive involvement is only possible by awareness building among the common masses of people which is less seen in the people living in India having a huge population. Because of less popularly about the concept of inclusion it is found absent among many of the masses living in the remote areas of the country. Even The United Nations Convention on the Rights of the Child (UNCRC) gives the right of every child that they can express their opinions and participate in decisions that affect their own lives. This Act emphasizes on children's rights of self-expression and participation regardless of their age, background, or disability. Researches has been done which explores the child's perspective of participation helps in making of international policies and has applications that results in collaborative care planning with the child (Lio et.al, 2019).

## **II. COMMUNITY INVOLVEMENT IN THE LIVES OF INDIVIDUALS WITH DISABILITIES**

Since a very long time individuals with disabilities are denied of their rights and liberties which is given to a normal human being. They are considered socially backward and were excluded from every event which used to occur in a community since past. With the globalization and social changes in the society. Now in the 21<sup>st</sup> century the concept have shifted from exclusion to involvement or in other terms inclusion. Inclusion of these individuals in a family but also the people around whom they are living their community. Community involvement is a concept which is needed to be included as an education lesson which is taught to the students when they enter classrooms to complete their education. Discrimination which is deep rooted in our Indian society can only be removed by taking positive approaches and educating a whole community about the current issues which are prevalent in the society today.

Human support services are provided to pursue the goal of community participation. Bringing people with disabilities to an array of civic programming which helps in delivering the social closeness which results in formation of heartland of life quality for this population of people (Milner. 2009)

Many campaigns are now resulting in bringing about positive thinking and feeling of empathy among the community members of a society. Think Differently, which was a very famous campaign which was headed by the Ministry of Social Development, became a social change campaign that works on to encourage, motivate and support a significant shift in the attitudes and behaviors towards individuals with disabilities. It functions all across community at all levels most important at national level it performs various activities such as:

1. Mobilization of personal and community action to the parts which are still untouched or unnoticed.
2. Bring in Change and transformation in attitudes which are pre-determined by the society and beliefs that is leading to individuals with disabilities to feel excluded.

3. Increase knowledge among the masses living in the locals of a state and making them understand about disability and the benefits of involvement of inclusive communities.

To make this happen this campaign has designed a platform to inform the further development of the Think Differently Campaign. Efforts like these can help in bringing social change in the society by efficiently making use of the community resources in a right way possible.

### **III. DISABILITY ISSUES AT COMMUNITY LEVEL**

1. There are certain common reported issues which generally occur in a community including mobility and accessibility problems, geographical, lack of time and vocational barriers, inadequate services and limitations in funding (Kuipers, Kendall & Hancock, 2001).
2. Current practices which are prevalent in the society still leave a feeling of strangers among people with disabilities in their community (Todd, G.E., Evans, and Bayer 1990) by failing to give strength to the service users to locate themselves within communities beyond where they are today. Which will help them to be able to experience the attributes of place identified which help in building a sense of community belonging.
3. Attitude of community towards Persons with Disability
4. Community related Issues faced by Persons with Disability - Aggression, Antisocial behaviour, Abuse and Social discrimination of persons with disabilities (PWD's)
5. Importance of Creating Awareness related to community issues
6. Importance of Community involvement & Resource Mobilization
7. Impact of technological developments on disability issues

### **IV. REVIEW OF LITERATURE**

Arakelyan et.al (2019) in their study titled Community-based participation of children with and without disabilities. The aim of this study was to do comparison of social and demographic features in community based participation among children with and without disabilities. The research design used by the researchers was a survey study. For which the researchers designed a questionnaire named as strength and difficulties questionnaire. The sample size used in this study was 5617 males and 5505 females aged between ten and twelve. Place of the study was United Kingdom. The research tools used in this study SPSS module was used to for item analysis. It was concluded that children with disabilities were likely to show psychosocial and behavioural problems and these problems were related to reduced level of participation in previous research.

Lio et.al (2019) in their study titled Understanding the Participation in Home, School, and Community Activities Reported by Children with Disabilities and Their Parents: A Pilot Study. The aim of this study was to discover whether self-reported frequency of participation

and give importance to activities which differ from the parents of children with disabilities and they themselves. The research design used by the researchers was semi structure interview method which was used to collect the data. In total 30 participants became part of this study in between the age of 6 and 13 in schools of Taiwan. The research tool used for this study was Picture My Participation (PMP). For this purpose researchers prepared a questionnaire. This study concluded that children showed less participation in community. On the other hand in school it was found that children participated more.

Tarvydas & Hartely (2018) in their book titled the Professional Practice of Rehabilitation Counselling. In the chapter three of disability rights and community. The main objective of this chapter was to review about the history of disability rights and to reflect on the power of disability culture. This chapter covered the following areas which are-Independent living movement, Disabilities studies, Disability culture these areas were mainly focused in order to help the rehabilitation advocates to locate the rehabilitation of persons with disabilities. As it was a chapter of book the author reviewed different aspects which were covered in the chapter. The studies which were reviewed to write the chapter were from the year 1959 to 2013.

Fisher & Purcal (2017) conducted a study titled Policies to change attitudes to people with disabilities. The aim of this study was to check the effectiveness of policies at different levels such as employment, education, government and health. To collect the data the researcher reviewed various policy papers from 2005 to 2011. This research focused on using multiple intervention at different levels. It draws implication about the effectiveness of intervention. It concluded that interventions at different levels can be effective in order to address the diversity of experiences in sector of disability and it also concluded that is need for replacement of negative attitudes to negative attitudes.

Simplican et.al (2015) conducted a study titled Defining social inclusion of people with intellectual and developmental disabilities: An ecological model social networks and community participation. The objective of this study is to emphasizes on the concept of social inclusion and to identify four major areas of which is organizational implication in context to social inclusion, inclusion of people having broader spectrum of disability, Inclusion of Intellectual and developmental disability social , active role of self-advocacy groups in addressing social inclusion. The authors reviewed different articles from the year 2003 to 2014. The results concluded and suggested that further research can be done encouraging and designing intervention which results in increasing of quality and quantity of inclusion in society.

Bedell et.al (2013) conducted a study titled Community Participation, Supports, and Barriers of School-Age Children With and Without Disabilities. The main objective of this study is to analyze patterns which are part of community participation and environmental factors which results in community participation for school-age children with and without disabilities. The research design used by the researcher in this study was Cross-sectional, descriptive, and exploratory study. Total number of participants who took part in this research were Parents (N-576), Children with disabilities (N- 282), Children without disabilities (N-294). Data was collected using ANOVA. The location where this study was conducted was United States and Canada. PEM-CY was a parent-report instrument/tool which was used by the researchers to check environment factors that affects the involvement

of school-age children. The study concluded that there is a requirement to support community participation of school-age children as in the study it was found that children with disabilities participate less. There is a need for participation and involvement of parents, environmental impacts were seen different areas such as-social, physical and cognitive.

Milner & Kelly (2009) in their study titled Community participation and inclusion: people with disabilities defining their place. The main objective of doing this study was to discuss various findings from the Community Participation Project which was started in New Zealand, where persons with disabilities got chance to reflect on what community participation and it mean to them. The research design used for this study was participatory action research. Total number of samples 66 out of which 19 were part of the focus group. Samples for the study was chosen from five different regions of New Zealand. Hyper Research qualitative software tool was used to collect the data of this project. It was found out that presence of persons with disability and adult in community spaces was necessary. Community participation spaces should be made more accessible physically and socially.

Verdonschot et.al (2009) in their study titled community participation of people with an intellectual disability: a review of empirical findings. The aim of this study was to examine community participation of people with Intellectual disability (ID). Research design and methodology used in this study was review based study which was carried out from the period of 1996 to 2006. Total 23 studies were given consideration by the researchers. The study further concluded that individuals with Intellectual disability participated only in limited areas of the community. It was found out that involvement of individuals with ID is much less as compared to the neurotypical individuals.

Niesz et.al (2008) conducted a study on the empowerment of people with disabilities trough qualitative research. The aim of conducting this research was to find the results of qualitative research in vocational rehabilitation leading to empowerment of Individuals with disabilities. The results stated that by increasing importance of consumer involvement and choice in all aspects of vocational rehabilitation service delivery results in bringing in the consumer empowerment to the forefront of research and program attempts.

Milner et.al (2004) conducted a study on community participation and inclusion of people with disabilities and defining their place. This research was action research project. Twenty eight (28) adults took part in this research at New Zealand. The data was collected by using research notes, digital recording and flip charts. To find out the results the researcher used Hyper Research qualitative software package. The results concluded that there can be five main elements which can help in bringing positive sense of belonging. This study choose to adapt to the collective strategy to make the environment socially and physically more accessible.

William et.al (2003) conducted a study titled a community based intervention for siblings and parents of chronic-illness or disability: the ISEE study. The main objective of this study was to examine the effect of intervention of children having chronic illness. Research design used in this study was random sampling method (experimental method) Total number of samples which was used were 252 out of which 150 were part of experimental group and 102 were part of control group. It was done for the children between the ages of 7 to 15 years of age. Tool used to do the data analysis was based on equation

panel analyses. It was revealed after the study that significant improvements were noticed of intervention of the experimental groups. Data showed that there is increase up to 15% on involvement of people in the community after intervention.

Cummins & Lau (2003) conducted the study titled Community Integration or Community exposure? A review and Discussion in relation to people with Intellectual disability. The main objective of this study was integration individuals with intellectual disability. The main objective of this study was to see the integration of individuals with Intellectual disability. Methodology and design used in this study was development of a fundamental program to integrate them into this programme. In conclusion it was found out that community integration will build a strong network and strengthen the abilities of individuals with Intellectual disability.

Kuipers, Kendall & Hancock (2001) in their study titled Developing a rural community – based disability service framework and implementation strategy. The main objective of this study was inspect the requirement of a sample of rural Queens-landers who had continue to show serious disabilities and the second objective was ,to identify suitable methods of providing rural rehabilitation to these people. The research design used for this study was survey in which the researchers collected the data by doing interviews. Methodology used by the researchers was Participatory Rural Appraisal (PRA). As it was a pilot study it was done on a small group 3,700 population of central Queensland. It was concluded that rural rehabilitation service delivery models should seek to: acknowledge the availability and role and value of skilled people who understand the local community; promotion of disability service skills among local community members; recognition of significance informal support processes; and more effectively in bridging the cultural gap between the city and rural areas.

Balcazar & Balcazar (n.d.) in their case study titled A Case Study of Liberation among Latino Immigrant Families who have Children with Disabilities. The objective of this study was to how a group of Latino parents carry forward a process of liberation along with the creation of empowering community views such as building critical awareness which leads to transformative action that resulted from a community-university partnership. The study was conducted in Singapore. The researcher used enquiry approach to conduct the research design. Case Study approach was used. Six parents of immigrant of Latino were interviewed. The authors reviewed various articles from 1981-2011. The study concluded that people can play a very important role in development of capacity to encourage social change.

## **V. CONCLUSIONS**

After reviewing above mentioned literatures and articles it can be concluded that community can play an effective role in lives of individuals with disability which will ultimately lead to social change in a society. Following are some conclusions which can be drawn after reviewing different articles:

1. Empowerment should be given to families and improvement should be done in providing parental access to community support programmes, parental counselling services can be provided to ensure participation of children in community participation, and financial

schemes can also help families to improve life chances and life styles of children with disabilities (Arakelyan et.al, 2019).

2. The positive attitudes and communication skills of professionals play very important role in giving assistance to the children in development of their self-expression and decision-making. This can happen when we use an appropriate tool, would further help in children to express participation experiences and desire to change activities (Lio et.al, 2019).
3. By using ecological model of social inclusion we can invite social inclusion in the society this can only be possible when there is promotion of various interventions are provided so that quality of services in society can be improved (Simplican et.al, 2015)
4. Adequate support to the school age children in all areas should be included in the environment will greatly enhance the participation and involvement of school aged children in the community (Bedell, 2013).
5. By welcoming the community to engage individuals with disabilities within those spaces where they feel safe and protected which exist. Examples of it can be included of a Danish project in which people with disabilities were given support to run a backpackers hostel, hosting and orientating visitors to their community (Milner & Kelly, 2009).
6. Meaningful social inclusion and a radical readjustment needs to be done apart from this the importance of peer relationships should be made aware about to community where we live in, it also involves the transformation of inclusion from an individual to the collective goal of people with disabilities (Milner & Kelly, 2009).
7. Occupational therapy, can be used as medium to help individuals with disabilities to give importance to each person within his or her environment. The person who receive occupational therapy services helps in making decisions about the social situations. The person receiving occupational therapy help him to develop relationship among persons family, and the occupational therapist in a collaborative partnership ,results in enhancing health and well-being through participation (Law, 2002).
8. Community based intervention can be very effective not only for children and individuals with disabilities but also individuals having chronic illness can also be benefited by this intervention. (William, 2003)

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