



DISABILITY & QUALITY OF LIFE OF CHILDREN WITH SPECIAL NEEDS: AN INTERPRETATIVE PHENOMOLOGICAL ANALYSIS

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Abstract:

Children with disabilities are one of the marginalized and debarred groups of children who experiencing extensive violations of their rights but every individual have a right to live freely and with dignity on the earth including the special need children. It is the disability which keeps such inequality apart from the fundamental human rights. In order to make all children including children with special needs enjoy their basic rights as envisaged in the UN's Universal Declaration of Human Rights, and lead a dignified, physically and mentally healthy and happy life, we have to improve their Quality of Life (QoL). Assessment of QoL is important because it gives voice to children. The present study focused on the QoL of children living with a disability. The study was conducted on special need children studying in special school of Varanasi city in India and Northwest Copenhagen city of Denmark. The method used is the phenomenological method which involves participant observation with the help of detailed field notes and interviews. The study revealed that disability is lived and experienced in a very personal way by the children with special needs and disability tends to adapt a better QoL to overcome lack of access and failure.

Keywords: Disability; Quality of Life (QoL); Children with special needs

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1. Introduction

“On the whole, social scientists have failed to provide consistent and concise definitions of quality of life. The task are indeed problematic, for definitions of life quality are largely matters of their personal or group preferences; different people value different things.”

George and Bearon (1980, p 1)

Quality of Life can be defined as *“the satisfaction of an individual’s values, goal and needs through the actualization of their abilities or lifestyles”* (Emerson, 1985). Quality of Life may be described as *“an overall assessment of well-being across various broad domains”* (Bjornson and McLaughlin, 2001 as cited in Doona, 2012). This may comprise physical, psychological, social, economic and spiritual dimensions (Sirgy, 1986). QoL in terms of Maslow theory may be defined as the hierarchical need satisfaction level of a given society. The choices play a significant role in defining our individual identities from everyday matters such as what to eat or wear, to the choice we make on large matters such as where to live or what kind of work to do (O’Brien, 1987). Every individual has a right to live freely and with dignity on the earth including the special need children. It is the disability which keeps such inequality apart from the fundamental human rights. United Nations Universal Declaration Human Rights (1948) included the following rights for Quality of Life:

- Right to be treated equally without regard to gender, race, language, socio-economic status etc.
- Right to education;
- Right to human dignity.

In order to make all children including children with special needs enjoy their basic rights as envisaged in the UN’s Universal Declaration of Human Rights, and lead a dignified, physically and mentally healthy and happy life, we have to improve their QoL. Assessment of QoL is important because it gives voice to children. Children with disabilities are one of the marginalized and debarred group of children who experiencing extensive violations of their rights. Discrimination arises not as a result children’s of disability but due to lack of understanding and knowledge of its causes and implication, in addition fear of contamination, negative views of disability, poverty, social isolation and an inaccessible environment. Prior to the categorization of disability and disabled people, the early history shows that all the mentally retarded, people were excluded from the society and termed as unproductive or deviant.

To have the benefit of the fundamental human rights and in order to improve their QoL they have to be given opportunities of a dignified, physically and mentally healthy and happy life. This can be achieved through social connectedness, sense of belongingness and with a careful environment. QoL is seen as the product of interaction of a number of different factors- social, healths, economic and environmental conditions which cumulatively and often in unknown ways, interacts to affect both human and social development at level of individual and societies. Therefore, maximum effort is

needed to support a social and educational policy that recognizes the similarity of lives of disabled children to those of other children, and that ensure their right as citizens rather than as disabled children to participate as fully in society.

For an organized effective system, after plan actions which Salamanca mentioned in 1994 is to develop schools which provide education for all children by equal opportunities to all children by giving equal opportunities to all physical, intellectual, social, emotional, linguistic and other developments all children should learn together and understand that they can socialize with other students with diverse needs. Therefore, pedagogical approach should be practically designed and visualized in the form of different workshops for teaching, which are under pedagogical & educational-training concepts in a limited area which can help to train them as tool for developments of an integrated and inclusive education system. The idea of health and physical fitness is one of the basic elements of human rights.

2. Review of Related Literature

The concept of QoL became widely used notion in National and International arenas during 1960 and 1970s, and began to seriously influence the field of Intellectual Disability in 1980s. During these three decades, observation, quality of life model and use in the field of intellectual disability, the description concerning QoL concepts generally fit into either social and environmental perspective (Andrew & Whitney, 1976; Davis & Fine- Davis, 1991; Paramenter & Donnelly, 1997) or personal well-being/individual perspective (Brown, 1997; Cummins; 1997; Goode, 1990). Kahneman, Diener & Schwarz (1999) considered QoL as a psychological state of 'well-being' and then to measure the QoL of groups or population in terms of average levels of expressed life-satisfaction or happiness. Layard (2005) and Marks & Shah (2005) found that subjective well-being or happiness is to measure social progress.

Within the field of disability, it has been argued that the QoL 'remains a notion rooted in the individual perceptions and values and that is '...primarily the perception of the individuals that reflects the QoL him /her experiences' (Schalock et al., 2002). As noted in the preamble 2007 UN Convention on the Rights of person with disabilities, 'person with disabilities continue to face barriers in their participation as equal members of the society and violation of their human rights in all parts of the world'. In a parallel development, other researchers have used frameworks based on Human rights instrument to define freedoms that people should enjoy a good society (Bradshaw et al., 2007; Emerson et al., 2008; UNICEF, 2007a). UNICEF used the framework provided by the UN Convention on the Rights of Child to select social indicators to characterize the well-being of children in the world's richer countries (Bradshaw et al., 2007; UNICEF, 2007).

The researcher has worked with the disabled persons in Denmark and Iran. Under the scope of pedagogical intention, the researcher had the opportunity to observe the level of QoL of the disabled persons and used the subject of local art and creativity

as important elements of providing creative workshop facilitates to them. The researcher worked at a job centre and conducted creative workshop for them to improve their QoL in Denmark. For 3 months, studying the environment and working with them in India. Researcher has found very few studies in the Indian context that studies quality of life of children with special needs. Thus, based upon the previous experience the researcher intends to undertake the research work to answer the question:

- What is the QoL of children with special needs?

3. Objectives of the Study

- To study the QoL of Children with Special needs.

4. Methodology of the Study

4.1 Research method

The study is a phenomenological study. It involves participant observation with the help of detailed field notes and interviews.

4.2 Population and Sample

In the present study, the population included all the children with special needs studying in various special schools of Varanasi City in India and Northwest Copenhagen city of Denmark.

In the present study, purposive sampling was used to select a homogenous sample of the participants for whom the research question was applicable. One special school and one (job Centre) integrated setting school have been selected from Varanasi city, India for the study. Besides this, one job Centre integrated setting school of job Centre from Denmark has been selected for cross cultural comparison.

4.3 Research Tool

Observational Checklist and Semi structured Interview Schedule

4.4 Procedure of the Study

The study was conducted in three Phases. These are:

Phase One: Observation of QoL and interview of their caretakers.

Phase Two: Implementation of creative workshop and yogic ASANAS.

Phase Three: Observation of QoL and interview of caretakers.

Observation /interviews were made at Job Centre in North-west Copenhagen, Denmark, Job Centre in Varanasi, India and Special School in Varanasi, India. The observations of the selected sample were conducted for 30 days for the assessment of their QoL. Thereafter, a comprehensive list of the indicators of the QoL was prepared which was followed up by the interviews of the caretakers.

| Superordinate themes | Sub-themes |
|-----------------------------|---|
| Relationship to materiality | Activation: work meaning and value Materiality: physical environment and the possibility of sensory experience |
| Relationship with self | Learning: to develop, acquire skills Identity: individual rooted in his / herself and commitment to the world around |
| Relationship with others | Care and Dialogue: to be able to express themselves to others and to be heard Sociality: to be to form social networks and affiliation |

Thereafter, the researcher designed a creative workshop and selected four simple yogic ASANAS i.e. Pranayama, Shawasana, Tadasana, Balasana. Then, the yogic ASANAS were organized for 30 days and the researcher made the observation /interviews after this period, to find out the influences of the workshop and yogic ASANAS on the QoL.

5. Analysis, Interpretation of Result and Discussion

The study was a phenomological study which involved participant observation with the help of the detailed field notes and interviews. So, in this study the researcher intensely studied the observable facts through her participation in the daily activities and engaged in the normal routines and partly gained an insight into the activists' everyday world through the practical task. In the process, the researcher learned that the study of the special needs children requires more participant observation than the non-impaired population. In addition, the researcher learned that the non-verbal communication needs to be very explicit and distinctive in its expression.

Observation 1

Participant No. 1 (Job Centre, Varanasi, India)

She is 16 years old overweight girl belongs to upper class family. She is talkative and stubborn. She doesn't get any physical activity at home, because they have many servants and not motivated environmentally. She is not taking initiative for any work her mother is completing every that she do not work at home. She is not active at doing tasks; she has remained on time to time to do it. She forgets things but remembers and recognizes her own things and does not intent to give it to someone else. She is unable to perform any task on her own, she needs help by someone. She did not like to play any sports with their peer groups.

After creative workshop and Yoga

She shown interest in choosing color of mat or the pictures on the wall and motivated for learning. Now she became more engaged in yoga activity. She is showing more interest in material which is more associated with yoga exercise. She performed better in the group activity. Now, her memory has improved. She became much more secure about herself and develops her physical awareness towards different situations in the life.

Observation 2

Participant No. 2 (Job Centre, Varanasi, India)

He is 18 years old and belongs to middle class family. He is poor in academic and average in social activities. He memorizes the songs which he likes. He is very keen in dancing and big fan of Michael Jackson and tries to imitate his dancing style. He likes to perform solo dance rather group dances. He is good in all vocational activities; he is good at bead stringing, crafting, and coloring of pots. He does physical exercise and yoga very well with lot of interest. He also does weight lifting.

After creative workshop and Yoga

He likes yoga and he can do a complete Surya Namaskar while doing the yoga. He is very focused and concentrated. He was now attentive on teaching and repeating continuously. His whole body was engage during training time. He is good in singing and dancing. He was very conscious boy about communication with others. Before workshop, he was not showing any special interest in games but after exercising in gym his tendency to physical activity is raised. His participants and communication has changed.

Observation 3

Participant No. 3 (Job Centre, Denmark)

Two women from the staff came and sit down with activists. One of them reads day's activities and explains each individual his/her activities designed for that particular day. The task usually consists of washing dishes, doing shopping or cooking. They explain.... what is today's plan? In addition, it is decided that the food has to be prepared jointly. The staff comes with pictures of their recipe suggestions so do the activists with their suggestions for the menu," Burning Love" the main food of this week.

It was observed that:

- Participants are free to choose activities for three weeks of workshop.
- Activists determined their function themselves.
- Participants have freedom to engage in an activity.
- Staff and the activists decide together the day activities.

Observation 4

Participant No. 4 (Job Centre, Denmark)

In the living room there are two activists in their wheel chairs watching Television along with a teacher who sits on the couch, watching video ("The One and Only"). This is a romantic comedy by Susanne Bier. One of the activists is laughing and other (moving) on his chair repeatedly and bends over his head. Researcher greets him and asks him....Is he enjoying? He bends his head through his forearm and looks at researcher while moving in the chair and trying to make some noise...at present he is composing music with his new guitar. There are several places where he plays for other students. For instance, Peter Sabro cultural house invites him for the cultural evenings

or here in the activity centre where he plays for them, some time he gets a hundred Dank-Kroner for a set. Money is necessary... he smile... it's hard to play, but you can express a lot with music. He starts singing song while others accompanied him.

The organization provides them opportunities to present themselves in front of others and express their creativeness. They were also invited for performance in various clubs. The participants get recognition by expressing them productively. Participated used this activity to express his feeling, emotions etc.

Interview 01 with Teacher (Job Centre, India)

I myself graduate from job centre, while he shows the only girl in the class; M is one of our students. She is 22 years and belongs to a poor family background. Her mother got many children and for many years, she didn't want to know about her because she did not look like her other children! But now her mother comes to see her on some holidays! M look at us, teacher said that she has behaviour disorder. We work hard to engage her more in the classroom, both in physical and mental level. We also work on her relationship towards others.

Earlier the participant's parents were not interested in their child but now a day they regularly visit the centre to meet her. The centre tries to engage participants like this are in more and more activities so that it increases their concentration. They also concentrate on building social relationship with each other.

Interview 02 with management (Job Centre, Denmark)

Dialogue is more important for general societal discourse in an organization of this type. There is always certain degree of segregation which reflects with these types of children. Our focus is to recognition and information of daily life to the participants... so that the user (activist) can learn when and how to communicate.

Management promotes dialogue among participants and with the staff, it is one of their priority objectives, and it is also mention as services of job centre. It is in the interest of the participants. Together this was a picture of institution and willingness to have integrated involvement in their work processes and structure. Organization provides a framework for both the possibilities and limits of power. It was also observed that expression of feelings and helpfulness and feeling of not being heard, affect the activists' relationship with the staff. It furthermore shows a sense of belongingness within the individuals especially as gender affiliation, both between the activist and in relation to educators.

6. Educational Implication

The findings and conclusion of this study have important educational implication for teachers, educational planners and policy makers which may be forwarded as follows:

The insight gained from the study will help in reconceptualising disabled children as citizen as capable of having a satisfactory material and spiritual life thereby leading to realization of the thought behind inclusive education and their right as equal citizen.

The study is important for policy formulation and educational planning for children with special needs. It will provide valuable information regarding the QoL Children with Special Needs and the influence of creative workshop. The insight gained from the study can be used to design educational program and curriculum for such children.

7. Suggestions for Future Researches

The researchers attempt to locate the budding areas for prospective researches. They are following:

1. Similar Investigation should be undertaken on students' suffering from other disabilities such as Hearing Impairment, Visual Impairment.
2. Comparative studies may be undertaken between the different disabilities with non-impaired students.
3. For the cross validation and comparison of the findings of this study, more cross-cultural, intra and inter-state studies may be carried.

7. Conclusion

The information gathered was interpreted according to the meaning and significant of the QoL of children with special needs. Through exploring and describing the QoL of the participants following findings were found.

- Motivation for engaging in creative workshop and yogic Ayasanas;
- Role of communication in maintain the QoL;
- Social connectedness having a positive effect on QoL of children with special needs;
- Services being received by the children with special needs;
- The economic situation of the family.

The slogan for the world report on disability was disabling barrier-break to include and this should promote an awareness that the key to ensuring the well-being of all the people with disabilities is to ...encourage the people with disability to adopt a better quality of life and overcome the lack of access and failures of provision that currently leaves so many millions of people on the margins.

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