Barriers of School Transition for Children with Disability: Lived Experience of Parents in Kathmandu Valley

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Abstract

This study aimed to explore the barriers of school transition for the children with disability from the parents' prospective. This study adopted qualitative method along with hermeneutics phenomenology. On behalf of philosophical orientation, multiple realities were ontological basis and lived experiences of participants were epistemological assumption. The construct of critical disability theory was applied in this study. Purposefully five parents were selected from Kathmandu Valley. Data sources included field notes, in-depth interviews and artifacts. Interviewed data were transcribed and categorized to develop themes. The results revealed that several challenges such as awareness, attitude, accessibility, misconception, infrastructure, lack of policy implementation and ill motivation about disability are the major barrier towards transition. The perception of parents towards special school and rehabilitation centres are inadequately supporting to smooth transition. This study may be valuable support for policy maker in ensuring the no child left behind for the welfare state.

Keywords: Critical disability theory, educational context, special school, rehabilitation centre, no child left behind

Introduction

Transition is important phase in the development of human beings from childhood to adulthood (Walker et al., 2012). In the transition of child from one position to other he/she has to face several challenges for their developmental activity. In going to transition phase , the departure becomes controversial and challengeable to move ahead because he/she has influenced by existing references (Winter, 2014). The transition takes place in the movement from one stage to another stage of situation including home to child care, day care center and school setting. Such type of transition hold particular significance in the life of child (Perry & Perry, 2015). The child lacks experience to navigate the new situation. Preschool transition can lead to uncertainty and anxiety for children with disability and their parents (Cook et al., 2018).School transition can create qualitative change in physical as well as psychological aspect in the support of care taker, parents and other stakeholders

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(Scarborough & Gilbride, 2006). Transitioning to new situation makes some degree of stress in the developmental flux of childhood development (Scarborough & Gilbride, 2006). The preschool transition for children with disability and children at risk are more hazardous and challengeable due to the deficit in adaptive self regulation ability and social skills that facilitate to transition (Hogansen et al., 2008).

In this context, parents of children with disability are negotiating with a bundle of stressful change such as disruption in service provision and support team staff (Welchons& Mcintyre, 2017). Preschool transition is foundation for later academic and social interaction of children on the way of educational development (Eckert et al, 2008). Preschool transition is sensitive period and necessary for later school success (Rimm-Kaufman et al., 2000). The importance of the preschool transition has been recognized powerful tools for the children with disability and gradually it has been reflected to local level along with social activities focusing childhood education (Davies & Beamish, 2009). The No child left behind legislation (Stallings, 2002) focuses on highlighting the necessities of addressing children's transition to basic school in both policy and practice.

The parents of children with disability may not understand about the service available and prerequisite for their child while transitioning to school (Ankeny et al., 2009). In some extent, they are unaware of legal provision due to lack of understanding about the information and awareness program (Walker et al.,2012). The perspective of parents need to be considered by school for identifying possible reason why children with disability are facing the challenges of transition to school and what are the coping strategies for smooth ways of transition (Timmons et al., 2004). In studying the literature only few studies have been conducted in the area of transition for children with disability especially in parents' perspective. In the case of Nepal no research has been accomplished for family experience in the transition of child with disability. So, major barriers of school transition for children with disability from the prospective of parents are the major concern of this study.

This study focuses on the following researcher question.
How do parents perceive about the preschool transition of children with disability?
What are the barriers to be faced by children with disability from the prospective of parents?

Underpinning the Literature on Involvement of Family in the Transition

The family involvement in transition activities of children with disabilities are comparatively more than normally developed children. Furthermore, families were found to have higher involvement for children with poor socio economic status(Welchons & McIntyre, 2017). The research report of Davish and Beanish in 2009 about the transition have shown that transition of children with disabilities from home to school is challenging especially in remote areas. Many school and vocational institution feel unable to offer option to children

with disabilities due to insufficient resource allocation and lack of expert to support teacher and learners (Perrig-Chiello & Perren, 2005). The children with disabilities are adhered to end their education without specific skill and knowledge for entering to job market and living independently (Hestenes & Carroll, 2000). The experience of families and meaning of collaboration held by individual families and highlighted the challenges(Villeneuve et al., 2013).

According to Dockett and Perry (2009a), the nature of education supports have changed for diverse disability to enable success. For the benefit of children with special needs, coordination among education, child care centre, developmental services are essential(Matthews & Rix, 2013).it is clear that the effective collaboration among parents, caretaker, professional and paraprofessional have significant effect on child development, schoolreadiness and educational achievement.

(Matthews & Rix, 2013) did one research using case study approach with three children with Down syndrome who are 3-4 years child. They interviewed parents of those children about how did their children participate in early intervention program to support learning. The findings reported as the role of communication, partnership with professionals, inclusion of children in mainstream program, parent's role as educators, the parents elaborated tension of their child to professional.

The research findings of King et al. (2005) revealed that the transition process is effective to the extent that children with disability are engaged and able to adopt their desired role. The roles are aligned with their strength and needs that fit the goals. Short term goals are the outcomes that are the foundation of successful transition that include enhanced knowledge of the self and future vision of the self, enhanced perception of support and more supportive environments.

Transition to school as a significant event

Research has asserted an influence on children's progress of the first year in basic school and has proposed that the transition to school is predictive of later school outcomes(Margetts, 2009). Transition to school for children with special education needs including those with disabilities and their families, brings multiple changes and new expectations for the parent, child and school staff. For parents, the relationship with the school may also be quite different to that experienced previously in preschool. Typically, early intervention and preschool services for children with disabilities are characterized by a family centered approach that incorporates regular communication and collaboration with parents (Dunst, 2002). In contrast, the relationship with the school may be different with reduced communication between the parent and school (Janus, Lefort, Cameron, & Kopechanski, 2007).School transition is also a vulnerable time for children with SEN, with challenges relating to

communication, problem-solving, and adaptive behavior (Welchons & McIntyre, 2014) and relationships with peers (Erwin & Guintini, 2000). For the child, there may also be the new experience of being evaluated in relation to the performance of others (Entwisle & Alexander, 1998). For teachers and school staff the transition brings expectations that they have the capacity to effectively support the child (Dockett & Perry, 2009).

Methodology

This study has adopted qualitative research method in which the interpretative phenomenology is the research design which intends to dig out lived experiences of participants which construct the shared meaning of similar experiences. This study embraces multiple realities as ontological basis and interaction and perception of participant as epistemological consideration. Five parents of children with disability from Kathmandu valley had been selected purposively as participant. The data had been collected by in depth interview with participant and participant observation. Firstly, the researcher made telephone call to all participants and requested to manage time for interaction. In the beginning of meeting, the participant tried to refuse my curiosity about children with disability. However, the participant gave positive response while he talked about legal provision and transition management strategies. The researcher talked about the major barrier perceived by participant in the preschool transition of children with disability. I tried to dig out the experience and feeling of participant in the school transition of children with disability by engaging with their involvement. Regarding to the overcome of ethical dilemma the participant were taken informed consent. In-depth interviews and participant observation were conducted for relevant information. Interviews with the participants were recorded by audio recorder. Recorded interviews responses were transcribed as verbatim and developed code. Similar codes were organized to generate theme. The similar themes were organized as a main theme of the study. Themes were illustrated on the basis of ground data and they were compared and contrasted with data to data and data to literature to draw the final conclusion.

Results and Discussion

Several challenges have occurred in the school for children with disability. Since the parents are facing financial crisis they need to work for overcoming hand to mouth problem. They experienced role transition in which they adopted new roles and face new challenges to adjust their child. The major barriers faced by children with disability for school transition from the parents' prospective have been discussed below.

Lack of awareness

There are different views about the disability condition of children in the community. Some people impose their thought with reference to medical model of disability. In such context one of the parents (P1) said as,

> My son is suffering from spinal cord injury associated with seizure disorder. He cannot stand and sit properly. He is always in sleeping position in the bed. He is speechless. Being a mother, I need to take care of him. He cannot express his will whatever he needs. I have made a schedule for feeding and toileting. I am very much worried about his life beyond our life. Our community is completely conventional and drop dogmatic thought towards disability.

From the above assertion, the parents of disabled children are in tension about their child behind their death. In Nepal, government has not established special child care centre for severe and multiple disabilities. The clear and visionary work plan has not been made for the management of severe type of disability. So, parents' anxieties have been increasing day by day in the absence of adequate and proper management.

Accessibility barrier

According to the enrollment situation of children, about 2% (CBS report, 2068) of children are out of school. These out of school children are from disability among of different categories. These type of students are unable to access in school because the special schools have not established in respective community especially in rural areas. In this context, another participant (P2) said as,

> We are from back warded community and do not have sufficient land. God has given us one child with physical disability. He cannot walk on foot. His lower part of the body cannot move. Now he is 13 years old and needs to go to school but we cannot purchase wheel chair. The school is far from our residence and there is no road appropriate to wheel chair to move. In such situation we cannot send our child with disability in to school. There is dense forest in the way to school and stream nearby school. I am afraid of wild animals; flood and landslide on the way feeling that education is not bigger than the child.

From the above assertion, the parents are not willing to send their child to school due to fear of flood, land slide and wild animals on the way to school. The children with physical disabilities need wheel chair but there is no appropriate way for wheel chair. In this way, geographical topography is one of the major impediments for transition of children with disability.

Misconception about disability

Unsocial thought that underestimate the child with disability is considered to be misconception about children with disability. Such type of understanding about disability obstructs for inclusion in society and creates inequality in community. In this relation P 3 urged as,

> There is one child with intellectual disability in my family. He often exhibits abnormal behavior in the family. His maladaptive behavior cannot be controlled easily and he is kept in cave with control mechanism. Sometimes he roams in community and shows misbehavior with distinguished person. Sometimes he is labeled by mad, idiot person along with teasing. Our community has not provided proper manner for him and always behaves like insane.

From the above statement, it is clear that, the children with disability are facing challenges of labeling and stigmatized thought from the community. The disabilities are treated on the basis of medical model and with motives of impairment. So the concept of community needs to be transformed by the thought asdisabilities are the result of social model and can be prevented with the help of social transformation.

Lack of policy implementation

Nepal has signed series of international conventions for ensuring rights of children to be educated. Special education council was formed in 1973 AD which focused on education of children with disability. Moreover, the government of Nepal passed special education policy in 2053 BS to achieve the goal of education for all by 2015AD and millennium development goal. Number of policy and provision have been made to ensure the access of children with disability in school but tendency of implementation is lacking behind due to the political instability in Nepal. In such context P4 stated as,

> I have heard that no child left behind is the constitutional provision of our country. Every child has right to education and they cannot be excluded regardless of caste, age, disability, ethnicity, economic status etc. To grasp of motto of education for all every child needs to be educated in least restrictive environment have seen that most of the parents of disabled children are suffering from the pain of their child condition and future.

In the above statement, there is no vacuum of policy and provision in paper for our country and rich in policy but side of effective implementation is lacking. As a result, most of the children who are at risk are still in out of schooling. Therefore, the mission of achieving education for all is residing back and not achieved in allocated time.

Infrastructure barrier

An environment favoring the child with disability for motivating in school culture refers to the infrastructure about school. Regarding to infrastructure, ramps, disable friendly class room, furniture, toilet, playground are the major parameters of infrastructure that pertains to the education of handicapped child. In the case of infrastructure, P5 expressed as,

> I am very much worried about my child who is suffering from cerebral palsy. There is no special school nearby our community. Observing the child of neighboring people sending their child in school smoothly, I like to send my child to school whether he is any situation. Once I asked head teacher to admit my child in school near my home, but he refused to do so. He said that school was not appropriate for my child. He suggested me to take my child another school. But I have heard that there is no ramp for moving the wheel chair.

From the above discussion, it is clear that every parent intends to send their children to relevant school for suitable education but they are unable to do so because of challenges in infrastructure for their child. Sometimes the school administrator refuses to admit the child with disability in the absence of disable friendly environment in school.

Lack of trained teachers

The acquired skill embodied to teacher for delivering effective teaching model in the class refers to training of teacher. In this contemporary situation of special school not all teachers are well trained and the children are not properly benefited. For this context P2 asserted as,

> I am unable to send my daughter to school because she cannot hear the voice of teacher. She always rejects to go to school when time becomes to school. She says I cannot understand the speech of teacher and difficult to acquire knowledge from school. When I wanted to talk about reading at school, she becomes irritated and said there was no teacher who could teach the children with hard of hearing.

By the above statement, it is clear that each and every teacher who teaches in inclusive school need to have training for teaching students with disability. If the teachers are not well trained for teaching to children with disability, the teaching won't be effective and inclusive.

Lack of professional experience

The effective approaches and strategies that are associated with teacher are the indicators of professional ethics. The various professional experience of teacher can pertain to enhance verities of skill in the teaching learning activities.

Along with the above statement, P3 expressed as,

> I donot have the knowledge of special school in my community am not aware about the special expert who teaches to deaf students with the help of sign language. The sign language interpreter in the community cannot serve without financial benefit. They take more money when teach to deaf students. In general school, there is not recruitment of sign language interpretation. Not all general teachers have the knowledge of sign language. In such condition my deaf daughter cannot be benefitted by school education. So why to send her to school?

By the above statement, it is clear that the public awareness about disability need to be developed in the community. Some of the parent are unknown about the professional who provides special skill to disable child as well as parents. In the community some Professional are delivering skill with high cost which is not affordable for some parents. So the fundamental right of handicapped child is not preserved due to financial imbalance in society.

Decline of trust towards school

The quality in education offered by school and effective delivery system can attract the intention of parents. The expectations of parents are very high especially for children with disability in school so that their children can survive independently after acquiring the knowledge. But regarding to this matter existing schools are losing their dignity in the eye of parents. In this context parent P4 urged as,

> My son is 4 years old. He cannot speak properly. He always wants to play alone and shows repetitive action. He avoids face to face contact while meeting to others. When I visited to doctor for check up to my son, doctor observes the characteristics and said my son is suffering from mild autism with emotional and behavior disorder. Then I admitted my son to the special school of autism and every day I used to go to school to bring my son. Every day I found my son remained unchanged and showing abnormal behavior with additional misconduct. Now I am not sending to school instead of I teach general skill at home myself.

In the above assertion, the parents dislike to bring their child in special school because they are not realizing advantage as expected for their child. The children with disabilities are facing one type of problem the organization are supplying unsupported activities. Furthermore, the special schools are not established in accessible areas by the government sector so the children as well as parents face challenges of transition to school. It is seemed that the parent's perception is not good about special school. Soin order to develop positive attitude, the school needs to adopt copping strategies for their child with disability on the basis of nature of disability.

Rehabilitation as local business

The settlement of disability with the help of rehabilitation centre founded either by local communities or by run by NGOs.Such types of centre are providing the support with residential facilities for mild and moderate type of disability. In this regard, parent P5 said as,

> My son is related with children with autism and he is unable to communicate with other. He cannot express his desire whatever he needsadmitted intoone rehabilitationcenter by thinking that he can speak and learn interpersonal skill. But instead I could not find any change even in 3 months later spent more money for the child in school. I think no all parents are able to pay like me. I realized that the rehabilitation centre established for business motives not for welfare basis.

In the assertion of parents, the children with disabilities are not benefitted with the provision provided by rehabilitation centre. The organization founders are doing business for the sake of money. The founder of rehabilitation centre are making viral to their organization for receiving donation from different agencies. In such case, the government has to establish authentic monitoring unit to see the organization whether they are contributing for the benefit of differently able children or leading their function as business motives.

Conclusion

This study investigated the parents' lived feelings in the transition to school of their children with disability. The study explored that the experience of parents towards special school was not satisfactory. There were bundle of challenges faced by disabled children in the academic course of life. Lack of awareness towards disability, infrastructure barrier, institutional barriers, attitudinal barrier, professional ninadequacies, education as economic motives,lack of trust,lack of policy implementation are the major barrier for handicapped child while accessing to school.In passing through the perception of parents, it is explored that the transition of children with disability from pre-school to school service is connected with pessimistic perception of family centeredness. The service and existing situation of school have increased non positive impact in the family oriented activities. The concreteness of policy implementation is lacking behind, as a result, handicapped children are marginalized from the fundamental rights to be educated. The study showed that parents have different perspective about the transition process is not unexpected. This research can play a crucial role in raising the issue that can enhance effective and successful transition to school for children with special needs. From the ecological point of view, parents' values and expectation can become the facilitators to overcome barrier to successful transition.

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