CHALLENGES AND PROBLEMS OF SCHOOL TRANSITION TOWORKPLACE FOR STUDENTS WITH AUTISM SPECTRUM DISORDER(ASD)IN ETHNICALLY DIVERSE FAMILIES

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Abstract

Research has consistently demonstrated that student's future in job success is contingent upon the quality of Transition from School to Workplace (TTS). Although TTS can be a stressful event for all families, it can be particularly stressful and problematic for families of children with disabilities. While there's a paucity of research concerning TTS for students with disabilities in general, there is almost no research related to TTS and Autism Spectrum Disorder (ASD). In addition, no extant research has examined these experiences within the specific context of ethnically diverse families. As such, the Aim of this study is to explore challenges and problems facing by parent, teachers and job providers in transition process for ethnically diverse families of ASD students using roundtable discussion and focus group methodology.Approximately 12 questions was posed to participants with probes, clarifying questions ask. After transcription verbatim and translation, analyses of qualitative data involving open coding. This study provides valuable insights into the understanding of TTS for families with children of ASD within the process in six areas of Knowledge, Role of Doctors, Policy, Accreditation, Attitudes, and Job Matching. It is hoped that this study will serve as basis to stimulate many more theoretically driven and culturally informed research and discussions about TTS for children with ASD in the future. Significant output of study provides some valuable insights into the understanding of TTS for families with students of ASDthat can be used as academic references to government and to review policy on disabilities for society and community well-being.

Keywords: Workplace Transition, Autism Spectrum Disorder, Ethnically Diverse Families

1. Introduction

Research has consistently demonstrated that student's future job success is contingent upon the quality of the transition to school (TTS) (McIntyre, 2006). Although TTS can be a stressful event for all families (La Paro, Kraft-Sayre & Pianta, 2003), it can be particularly stressful and problematic for families withchildren with disabilities. While there's a paucity of research concerning TTS for students with disabilities in general (Janus et al., 2007), there is almost noresearch related to TTS for children with Autism Spectrum Disorder (ASD). In addition, no extant research has examined these experiences within the specific context of ethnically diverse families.

The statistic showed that some 47,000 people in Malaysia were autistic and the number is expected to increase every year (Mingguan Malaysia, 2013). It is also estimated that four out of every 10,000 suffer from severe autism (Rani et al., 2015).Autism is a Spectrum Disorder because it involves one of psychiatric illness, (DSM 5[th]editon). It is characterized by three features: Impairment of social interaction, Impairment in communication, and Restricted,

repetitive and stereotyped pattern of behaviour, interests, and activities (American Psychiatric Association, 2013)

Among one of the most common factors cited for the increase in ASD is the ever changing diagnostic criteria for this spectrum of disorders (Honda et al., 2005). Past epidemiological studies are grounded on a review of medical records, which are frequently incomplete or non-existent, depending on the province of a country's healthcare system and the number of clinics with experts qualified to diagnose childhood disorders.

At present, there is no local epidemiological study on ASD prevalence in Malaysia (Tina et al., 2014), The prevalence study of ASD in Malaysia relies on the survey conducted by local parties. A literature search conducted by Tina et al. (2014) on the prevalence study of ASD through database, including Science Direct, ProQuest and Web of Science and Medline found that all the prevalence studies were primarily done in the Western and European nations. Therefore, no report published on autism prevalence study in the Southern Asia which includes Malaysia and Indonesia. Studies that were conducted in Malaysia are more general, which covers a range of disabilities with limited focus on ASD study. The transition from elementary to secondary school involves a major ecological shift, which causes a number of demands on a child's social, intellectual and organisational capacities (Coffey, 2013). This particular transition can be seen as one of the most challenging gaps in a student's educational career (Zeedyk et al., 2003).

The aim of this study is to explore challenges and problems facing by parent, teachers and job providers in the transition process for ethnically diverse families of Autism Spectrum Disorder students using roundtable discussion and focus group methodology.

2. Problem Statement

The awareness of ASD in Malaysia is low and this could be the contributing factor of why autism is not understood and professed by the society (Dolah et al., 2012). Individuals who could not understand ASD often visualize them as selfish, slow, distant and odd (Dolah et al., 2011). The lack of awareness towards ASD often causes people to misconstrued them as mental illness (Mansor, 2010).

The prevalence of Autism Spectrum Disorders (ASD) in Malaysia is as below:
  – 1.6/100, Malaysia Health Technology Assessment Section (MaHTAS, 2014).
  – 1/625 children, Survey (Azizan, 2008).
  – 1/600 Malaysian, Ministry of Health (2004).

There has been a 30% increase in the organization's intake of individual's with autism in the past three years (National Autism Society of Malaysia (NASOM), 2013). However, the current prevalence remains unknown (Nornadia et al., 2013). In Malaysia, ASD Students are educated in special education classes that are in normal mainstream schools (Integrated Programme for Learning Disabilities). In reference to that, there has been a considerable increment in the amount of effort in instilling awareness among Malaysians. However, this issue still goes unnoticed (Dolah et al., 2012).

Studies examining school transition for students with disabilities have highlighted numerous stressors that maybe experienced by parents. These include "unknowns" related to transition (e.g."what will the attitude of job staff be toward my child? Will the other students accept my child? Will my child be able to cope in the job situation?" etc), the need to communicate with

a new set of professionals and multidisciplinary teams after the transitions (Podvey, Hinojosa & Koenig, 2013), and moving from family-oriented and supportive school system, and moving from the auspices of one government department to another (Janus et al., 2007). Though these concerns characterize families of children with diverse special needs, the unique nature of ASD may result in a particularly difficult transition and unique additional concerns for these parents. ASD is a developmental disorder characterized by deficits in socio-emotional reciprocity and communication (verbal and non verbal), as well as the presence of restricted interest and repetitive behaviours (American Psychiatric Association, 2013). In addition, between 38% and 50% of individuals with ASD also have an intellectual disability (Centers for Disease Control, 2012). The transition literature indicates that there are number of skills that children with special needs should demonstrate to increase the likelihood of a successful transition to school (TTS). These include independent following instructions, and basic social and communication abilities (Chadwick & Kemp, 2000; Janus et al., 2007).However, these are precisely the areas of difficulty that characterize children with ASD. In addition, individuals with ASD tend to have extreme difficulty in generalizing learning, and thus skills learned in one setting are less likely to be transferred to school setting. To date, however, it remains unclear how parents of children with ASD conceptualize a successful TTS in which elements of the TTS are experienced as positive or negative. Cultural values and believes have been found to significantly affect the ways stressors are perceived and experienced, and thus, affect the subsequence patterns of coping responses with these stressors (Kuo, 2011, 2013). These considerations have prompted several researchers to advocate for autism research among culturally diverse groups (Mandell & Novak, 2005).

3.Literature Reviews

Research has consistently demonstrated that children's future school success is contingent upon the quality of the transition to school (TTS; Schultin, Malone & Dodge, 2005; McIntyre, Blacher & Baker, 2006). Although TTScan be a stressful event for all families (La Paro, Kraft-Sayre & Pianta, 2003), it can be particularly stressful and problematic for families of children with disabilities (McIntyre et al., 2010). While there is a paucity of research concerning TTS for student with disabilities in general (Janus et al., 2007), there is almost none related to the transition of student with autism spectrum disorder (ASD). In addition, no extant research has examined these experiences within the specific context of ethnically diverse families. Given the increasing ethnic diversity in Canada and the United States (Statistics Canada, 2007; Shrestha & Heisler, 2011), research exploring the TTS process for ethnically diverse families of children with ASD is imperative. In this study, we address this gap by exploring the TTS experience for ethnically diverse families of children with ASD using a qualitative focus group study method that involved multiple informants including parents, school teachers and job providers.

Ecological models are considered to be particularly well suited to research with both multicultural and multiethnic groups, including the study of TTS (Sontag, 1996; Rimm-Kaufman & Pianta, 2000). Bronfenbrenner's (1979b) Ecological Systems Theory is dynamic, describing developmental outcomes as a function of ongoing bidirectional interactions between individuals' characteristics (e.g., temperament, social responsiveness) and their ecological contexts (e.g., cultural values, school-based protocols) over time (Bronfenbrenner, 1992; Rous, Myers & Stricklin, 2007; Podvey et al., 2013).

Previous research has demonstrated, TTS needs to be viewed as a process rather than a discrete event (e.g. Podvey et al., 2013), one that begins the year before, and continues well

after the new school year has begun. It is within this process that needs and gaps in each of the four identified areas of 'Relationship Building, Communication, Knowledge, and Support' can be addressed to ensure positive transition outcomes. As Podvey et al. (2013) pointed out, recommendations regarding transition practices have been in the literature for the past two decades. However, they are often not translated into positive transition experiences for children with special needs. The nature of ASD, in particular, presents some unique challenges and needs (Forest et al., 2004).

4. Methodology

This research was done in Two (2) Phases:

Phase 1: Exploration of meanings, ideas and concept of TTS from diverse families with ASD children.

Phase 2: Researcher usedthe method of gathering data by organising a roundtable discussion and Focus Group Discussion (FGD).

Sampling:
Purposive sampling with 27 participants involved in the discussion which comprised of parent who have ASD children (6), special education teachers (6), child psychology/development lecturers (7), government social welfare officers (2), NGOs (3), and job providers (3). They are from multiethnic, multicultural groups in Malaysia namely Malays, Chinese, Indian, Kadazan, Bajau, and Murut.

Location:
Faculty of Psychology and Education, Universiti Malaysia Sabah, Kota Kinabalu, Sabah, East Malaysia.

Procedure:
Focus Group Discussion (FGD) and In-depth interview was carried out with parent, teachers and job providers. Approximately 12 questions was posed to the participants in each group with additional probes or clarifying questions being ask whenever appropriate. The roundtable discussion and group session lasted approximately three (3) hours.

5. Data Analysis and Findings

Digital audio recordings of the focus groups were transcribed verbatim in the language used in the focus group and double-check for accuracy. After transcription and translation, the analyses of the qualitative data was conducted adhering to the procedures recommended by Strauss and Corbin (1998). The data are examined at three different levels involving open coding, axial coding and selective coding. That is, each transcript is first reviewed line by line and initial codes was derived (open coding). These codes are then subsumed into broader categories (axial coding). Finally, the main categories of interest for this study was selected (selective coding) and subsequently organize into the overarching themes for the results (Strauss & Corbin, 1998). To ensure credibility and reliability of the codes and categories, each transcript are reviewed and coded independently by the lead researcher, co-researcher and a research assistant. Coding, categories, and resulting themes are then discussed among the researchers to reach a consensus.

6. Results

Six (6) overarching themes and subthemes were developed from the open, axial, and selective coding process. These were labelled Knowledge, Role of Medical Doctors, Policy, Accreditation, Attitudes of Parent and Job Matching respectively.

1) Knowledge

The first theme to emerge from the data was *Knowledge*. This theme encompasses parents' knowledge about autism and teachers' knowledge about teaching students with ASD. As a Kadazan-speaking mother expressed:

"At that time I knew nothing. I only knew that this child is particularly active and his language ability developed slowly. But I didn't [think] that there was anything wrong with his language ability, since many people say that boys usually develop language skills late. I didn't know what "autism" is. I had no idea about it...I remember...I asked my husband "what is autism?" He explained its meaning in Kadazan to me. I had no idea what its symptoms are, how it will develop in the future"

Teachers in roundtable discussion believed they were lacking in knowledge. They indicated the problem was more pervasive than simply lack of training:
"I think that it's a ...lack of autism training at all levels right now in education and that impacts transition everywhere!"

2) Role of Doctors

There are limitations in the process of diagnosis done by doctors. Majority of participants revealed doctors did not diagnose correctly when examine their ASD children. As one parent commented:
"Doctors continue to report my child as learning disabilities but did not diagnose specifically...!"
"Developmental Paediatrician can diagnose this disorder but not many..."
Researcher felt the important of having child specialist to do diagnosis and early intervention for ASD children. Most participants felt that Developmental Paediatrician is the right specialist to do diagnosis.
When a child has been confirmed ASD, it is a requirement for a child to receive early intervention immediately after diagnosis. As a Tamil-speaking mother expressed:
"Basic screening tool for autism, it is even available online which is basic questionnaires. We can test to 18 months until 2 years old children. But the system still didn't take thing into that one early intervention"

3) Policy

Another challenge in the transition process is about unclear implementation policy. Job companies who employed workers with learning disabilities revealed that no clear policy on this transition program. In addition, without existing transition centre itself make it worst. As one of job provider commented:
"Sabah Cheshire Home [NGO] or even school don't have enough manpower. Without that, it's difficult to train this disable on how to do work, communicating, marketing and entity to work later on."

4) Accreditation

There are only a few Non-Governmental Organizations (NGOs) that give accreditation certificate to ASD students after completion their training and limited to selected courses

only. Training centres are not accredited to offer certificate. One of the job providers stated they can only offer training, but not to give certificate because they are not an accredited centre. However, one teacher shared her views that the Ministry of Education has plans to handle this accreditation issue. As one lecturer commented:

"Ah...h...h...this accreditation certificate is difficult! Even now Sabah Cheshire Home has to work together with certified college to run pastry skills programme. They will get certification level 2 after 9 months...that's it!"

5) Attitudes

Parents play an important role in transition process. Attitudes of parents emerged as a dominant theme. As an English-speaking teacher stated:

"A lot of parents are very protective over their children. We have to do counselling with them by showing the ability of their children"

Teachers also commented on their impressions of having to be very careful about what they said to parent and how they phrased things. It is highly sensitive:

"...and you just want to say what you really think but you feel like you have to phrase it all...Because you don't want to burn any bridges...you gotta stayed involved."

6) Job matching

Job matching is an effort and action to shift nature or kind of job and rearrange it so that it is suitable to person with disabilities, and with permission. The Job matching process is important to support this transition process. Children who are enrolled in a special education class were given co-curriculum activities by Ministry of Education. They were given skills in gardening, arts and crafts, baking, sewing, etc. But, when they are out to job market, these skills are not matched and consistent with what they have learnt in classroom. Thus, job matching is deemed necessary for ASD students so that whatever job given to them can match with skills they have learnt in schools. As a Mandarin-speaking mother expressed:

"Many registered with Department of Manpower but that job matching is difficult...not many bosses want to take ASD workers"

Conclusion

The purpose of this study was to explore challenges and problems facing by parent, teachers and job providers in transition process for ethnically diverse families of Autism Spectrum Disorder students using roundtable discussion and focus group methodology. Results revealed challenges and problems did exist in the transition process from school to workplace for ASD students. As previous research has demonstrated, TTS needs to be viewed as a process rather than a discrete event (e.g., Podvey et al., 2013), one that begins the year before, and continues well after the school year has begun. It is within this process that needs and gaps in each of the six identified areas of *Knowledge, Role of Doctors, Policy, Accreditation, Attitudes* and *Job Matching* can be addressed to ensure positive transition outcomes.

ASD students need transition training towards workplace for smooth and effective transition. Teachers also require in-service training in understanding ASD and educational interventions, a finding consistent with much research (e.g. Whitaker, 2007; Starr & Foy, 2012). This can go a long way toward dispelling fears and anxieties of both parties.

Parents should be aware of their child development. If it can be detected and diagnosed early, intervention can be done as early as possible. Behaviour modification can be done

immediately to enhance development and social ability of ASD children. Screening process and diagnosis need to be done specifically by child development specialist and developmental paediatrician; not only to diagnose in general, but thorough medical examinations and investigations to confirm that ASD children have problem in learning difficulties.

Although the current study provides some valuable insights into the understanding of TTS for families with students of ASD, much research remains to be done. In addition, larger qualitative and quantitative studies that will be done in the next phases of study that specifically include families of diverse cultural and ethnic backgrounds along with the other TTS stakeholders would lend further credence to and extend the current findings. Studies conducted in multiple languages would be particularly valuable to ensure that parents often underrepresented in autism research would have the opportunity to participate.

The findings of the current exploration should be interpreted with caution in view of a number of limitations. First, this study was based on volunteer participants and convenience samples, and thus it is not clear whether the views of the participants represent the TTS experiences of the larger population. Second, it is important to note that the educational level of participants in this study was quite high. This too might have played a role in the experiences and perceptions of the current participants.

In conclusion, to our knowledge, this study is the first to specifically recruit and conduct roundtable discussions and focus groups with parents of students with ASD, and teachers from diverse ethnic and linguistic backgrounds. As such, it provides an important, initial window into the TTS experience of culturally diverse families. Moreover, the present study contributes to the existing ASD literature by including multiple perspectives from various TTS stakeholders and by providing a more comprehensive understanding of the TTS process. Finally, we hope this present study will serve as the basis to stimulate many more theoretically driven and culturally informed research and discussions about TTS for students with ASD in the future.

References

i.   American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn, Washington, DC: Author.

ii.   Azizan, H., 2008. *The Burden of Autism*. Available at: http://thestar.com.my/news/story.asp?file=/2008/4/27/focus/21080181&sec=focus [Accessed: August 4, 2010]

iii.   Bronfenbrenner, U., 1992. Ecological Systems Theory. In Vasta, R. (ed.) *Annals of Child Development, Six Theories of Child Development: Revised Formulations and Current Issues*. London, England: Jessica Kingsley, pp. 187-249.

iv.   Centers for Disease Control. 2012. Prevalence of Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report*, 61, pp. 1-19.

v.   Chadwick, D. & Kemp, C., 2000. Essential Skills for Survival in A Mainstream Kindergarten Classroom. *Special Education Perspectives*, 9, pp. 27-41.

vi.   Coffey, A., 2013. Relationships: The Key to Successful Transition from Primary to Secondary School? *Improving Schools*, 16(3), pp. 261-271.

vii.   Daley, T. C., Munk, T. & Carlson, E., 2011. A National Study of Kindergarten Transition Practices for Children with Disabilities. *Early Childhood Research Quarterly*, 26, pp. 409-419. doi:10:10.1016/j. ecresq.2010.11.001

viii.   Dolah, J., Yahaya, W. A. J. W., Chong, T. S. & Mohamed, A. R., 2012. Identifying Autism Symptoms using Autism Spectrum Quotient (ASQ): A Survey Amongst UniversitiSains Malaysia Students. *Procedia-Social and Behavioral Sciences*, 64, pp. 618-625.

ix.   Forest, E. J. & Homer, R. H., 2004. Transitions for Young Children with Autism from Preschool to Kindergarten. *Journal of Positive Behavior Interventions*, 6, pp. 103-112.

x.   Honda, H., Shimizu, Y., Imai, M. & Nitto, Y., 2005. Cumulative Incidence of Childhood Autism: A Total Population Study of Better Accuracy and Precision. *Developmental Medicine & Child Neurology*, 47(01), pp. 10-18.

xi.   Janus, M., Lefort, J., Cameron, R. & Kopechanski, L., 2007. Starting Kindergarten: Transition Issues for Children with Special Needs. *Canadian Journal of education*, 30, pp. 628-648.

xii.   Kuo, B. C. H., 2011. Culture's Consequences on Coping: Theories, Evidence, and Dimensionalities. *Journal of Cross-Cultural Psychology*, 42, pp. 1082-1102. doi:10:1177/002022110381126

xiii.   Kuo, B. C. H., 2013. Collectism and Coping: Current Theories, Evidence, and Measurements of Collective Coping. *International Journal of Psychology*, 48, pp. 374-388. doi:10.1080/00207594.2011.640681.

xiv.   La Paro, K., Kraft-Sayre, M. & Pianta, R., 2003. Preschool to Kindergarten Transition Activities: Involvement and Satisfaction of Families and Teachers. *Journal of Research in Childhood Education*, 17, pp. 147-158.

xv.   LoVullo, S. V. & Matson, J. L., 2009. Comorbid Psychopathology in Adults with Autism Spectrum Disorders and Intellectual Disabilities. *Research in Developmental Disabilities*, 30(6), pp. 1288-1296.

xvi.   Mansor, R., 2010. *The Kidzcare Concert*. Available at: *http://www.pmo.gov.my/datinrosmah/_view_speech.php?submission_id=193*

xvii.   McIntyre, L., Eckert, T. L., Fiese, B. H., DiGennaro Reed, F. D. & Wildenger, L. K., 2010. Family Concerns Surrounding Kindergarten Transition: A Comparison of Students in Special and General Education. *Early Childhood Education Journal*, 38, pp. 259-263. doi:10.1007/s10643-010-0416-y

xviii.   Neik, T. T. X., Lee, L. W., Low, H. M., Chia, N. K. H. & Chua, A. C. K., 2014. Prevalence, Diagnosis, Treatment and Research on Autism Spectrum Disorders (ASD) in Singapore and Malaysia. *International Journal of Special Education*, 29(3), pp. 82-92.

xix.   Podvey, M., Hinojosa, J. & Koenig, K., 2013. Reconsidering Insider Status for Families during the Transition from Early Intervention to Preschool Special Education. *The Journal of Special Education*, 46, pp. 211-222.

xx.   Quintero, N. & McIntyre, L., 2011. Kindergarten Transition Preparation: A Comparison of Teacher and Parent Practices for Children with Autism and Other Developmental Disabilities. *Early Childhood Education Journal*, 38, pp. 411-420. doi:10.1007/s10643-010-0427-8

xxi.   Rani, N. M., Legino, R. & Kamaruzaman, M. F., 2015. *A Theoritical Study on the Influence of Visual Schedule towards Children with Autism Independent Life and It's Chances Through Mobile Technology.*

xxii.   Razali, N. M., Toran, H., Kamaralzaman, S., Salleh, N. M. & Yasin, M. H. M., 2013. Teachers' Perceptions of Including Children with Autism in a Preschool. *Asian Social Science*, 9(12), p. 261.

xxiii.   Rous, B., Myers, C. & Stricklin, S., 2017. Strategies for Supporting Transitions of Young Children with Special Needs and Their Families. *Journal of early Intervention*, 30, pp. 1-18.

xxiv.   Starr, E. & Foy, J. B., 2012. In Parents' Voices: The Education of Children with Autism Spectrum Disorders. *Remedial and Special Education*, 33, pp. 207-216.

xxv.   Sontag, J., 1996. Toward A Comprehensive Theoretical Framework for Disability Research: Brofenbrenner Revisited. *The Journal of Special Education*, 30, pp. 319-344.

xxvi.   The National Autism Society of Malaysia (NASOM). 2013. Available at: http://www.nasom.com.my/index.php?option=com_content&view=article&id=58&Itemid=5

xxvii.   Whitaker, P., 2007. Provision for Youngsters with Autistic Spectrum Disorders in Mainstream Schools: What Parents say-and what Parents Want. *British Journal of Special Education*, 34, pp. 170-178.

xxviii. Zeedyk, M. S., Gallacher, J., Henderson, M., Hope, G., Husband, B. & Lindsay, K., 2003. Negotiating the Transition from Primary to Secondary School Perceptions of Pupils, Parents and Teachers. *School Psychology International*, 24(1), pp. 67-79.