

Navigating Psychological And Structural Family Support For Children With Disabilities In Malaysia

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Abstract

Purpose - This paper aims to review the literature related to support on families in caring for children with disabilities in Malaysia.

Design/methodology/approach - A systematic search of studies published between 1994 to 2022 in American Academy of Pediatrics, Oxford University Press, Cambridge University Press, Routledge, SAGE Online, Springer Link, Taylor & Francis Online, Humanities and Social Sciences Collections, Wiley Online Library and Health Collections was undertaken to examine the support and challenges faced by families in caring for children with disabilities.

Findings - Studies shown that family members faced a lack of psychological and structural support in caring for children with disabilities. This has led to a variety of issues and challenges including social exclusion, stigma and discrimination, lack of guidance in education and challenges in healthcare settings for children with disabilities. Addressing these issue and challenges is fundamental in ensuring these children social, physical and mental needs are being met thus allowing them to grow into an outstanding individual. **Originality/value** - This paper is currently not under consideration, in press or published elsewhere. Functioning teamwork and collaboration between various agencies by increasing psychological and structural support for families and children with disabilities could can reduce negative implications on families and children with disabilities and alleviate their social functioning and well-being as well.

Keywords - Support, Challenges, Families, Disability, Children with disabilities.

Introduction

Family remain as a vital part of social institutions and can directly influenced children's growth and upbringing. That aspect also applies to children with disabilities in need of support from their families in particularly as they are growing up. The situation in Malaysia describe most families with disabled children in Malaysia have the tendency to overprotect their disabled children by limiting their exposure to the outside world (Islam, 2015). This situation worsens in cases where a family is hit with poverty and illiteracy on capabilities and abilities of their children. This scenario result in children with disabilities to be deprived from their fundamental needs including health, and recreation (Islam, 2015).

Existing notion that family members considered children with disabilities as burdens also provokes a dysfunctional environment for children with disabilities to flourish and prosper (Tharshini, Ibrahim, Amin, & Zakaria, 2016). Thus, a deeper understanding of disability experience within the dynamics of family relationships needs to be understood beyond the current existing parameters such as structural and attitudinal barriers. A complex analysis of the disability phenomena that is able to investigate different contexts, meanings and experiences for the people affected by disability should be pursued (Amin, Suhaimi, Jamiah, & Iqbal, 2018)

Method

Literature review for this paper was derived from an extensive search of a variety of databases, which included research papers from the American Academy of Pediatrics, Oxford University Press, Cambridge University Press, Routledge, SAGE Online, Springer Link, Taylor & Francis Online, Humanities and Social Sciences Collections, Wiley Online Library and Health Collections published between 1994 to 2022. The search terms used in this paper included 'children with disabilities', issues and challenges of children with disabilities, lack of support for families and children with disabilities. At first, the search was focused down to find research papers written within Malaysian and Southeast Asian context but only several research papers were found. Thus, research papers from other regions, as long as related were included. 56 articles including academic journals, books, research papers and reports were identified, reviewed, and extracted to support this review by the research team.

From the database search 92 articles including books and report were obtained. Authors used Endnote version 7.1 reference manager software to import the details of these articles and 37 articles were deemed irrelevant and removed by Endnote. All authors reviewed the remaining 55 articles to extract the relevant quintessential data to support the objective of this systematic review.

Prior to the commencement of writing this paper, ethics approval was obtained from the Human Research Ethics Committee (JEPeM), Universiti Sains Malaysia (USM/JEPeM/19120969).

Results

The systematic review of literature has resulted in different studies that focus on issues and challenges faced by families with children with disabilities. Discussion on this review will be focused on studies regarding family support in caregiving for children with disabilities. This review was focused down into the lack of psychological and structural support for families and children with disabilities. Issues and challenges that families and children with disabilities faced including social exclusion, stigma and discrimination and unmet healthcare needs. The results of the studies will be discussed critically in the context of this review.

Malaysian Perspective of Disability

Malaysia's diverse multicultural population has prompted a complex understanding of disabilities, particularly on the topic of stigma and religion (Sheri, 2015; Ling, 2007). According to Chan (2012), a study in Sarawak on children with down syndrome reported that Muslim families perceived giving birth to children with disabilities as a predestined gift from God and it will benefit them in this life and in the hereafter. In other Malaysian cultural beliefs, having children with disability is the result of bad actions or decisions throughout their life or during pregnancy, for example from the Iban community in East Malaysia who believe that a child becomes disabled because the mother had broken certain taboos or cultural laws in their tribe (Chan, 2012; Mamba, 2010; Ling, 2007). However, in some cases involving Malays and Chinese families, physical and supernatural or religious causes ranked lower than emotional, social and psychological causes of disability as the primary cause of disability in Malaysia (Edman & Koon, 2000).

Chinese communities in Asia also hold similar traditional beliefs of Karma and view having disabled children as a manifestation of their ancestors' past moral misconduct (Ngo, Nguyen, & Lawrence, 2012). Furthermore, in traditional Asian societies, traditional healers were rooted in local belief systems to be able to treat children with disabilities (Botros et al., 2006; Lauber & Rössler, 2007). Permanent chronic illnesses are also viewed as a spiritual punishment for involving themselves in witchcraft or resulted from a demonic possession or ancestral heritage (Lauber & Rössler, 2007).

This contributed to the perception of stigma and discrimination that families with children with disabilities have to deal with throughout their life and the depth of religion and spirituality are embedded into the understanding of disability in Malaysia.

Familial Issues and Challenges in Caring for Children with Disabilities

In Malaysia, a traditional family unit consider caring for own family members as a tradition to guarantee a positive well-being of the family members (Bakar et al., 2014). The same practice applied to children with disabilities or other individual with chronic illnesses. However, coexisting with their families give birth to many external and internal issue and challenges within their own family constitution and problems that comes from broader society as a whole.

Healthcare Needs

In middle-income countries such as Malaysia, estimated percent of children with disabilities with unmet healthcare needs were well documented. Unmet needs on recovery and rehabilitation services is approximately 50% to 75%, while children with disabilities in need of assistive devices up to 60% to 80% (Tan, 2015; Azman et al., 2020). Furthermore, half of the population of children with disabilities in middle-income countries have unmet needs including dental services, speech therapist, and home care nurse. The primary reason for a prominent lack of healthcare needs is the unavailability and inaccessibility of services particularly in terms of available services being too expensive and inability to access the services geographically (Tan, 2015).

On top of that, according to UNICEF (2014) logistical challenges such as the lack of competent medical staff, and limited resources restrict children with disabilities and their families to access healthcare services. Furthermore, the scarcity of healthcare providers such as physiotherapists, occupational therapists, clinical psychologists and psychiatrists who are well-verse in working with children with disabilities across multiple health centres in Malaysia remain limited. This scenario prompt health care providers to restrict their human resources only to restricted screening, intervention and rehabilitation which will later impact the overall state of healthcare received by children with disabilities. The lack of equal distribution of healthcare centres and infrastructures between rural and urban areas continues to disrupt the delivery of healthcare and rehabilitation especially in rural and urban poor communities (UNICEF, 2014; Ali et al., 2020).

On top of that, children with disabilities have suffered from poor dental health and nutrition which highlights the importance on those services (Norwood, 2013; Sullivan, 2002). According to Lewis (2009), dental care

is listed as one of the needs among children with disabilities in Malaysia. These demonstrated that dental health care for children with disabilities are not viewed as fundamental by medical professionals compared to other children with other medical complication.

Furthermore, children with disabilities in Malaysia face accessibility issue in receiving speech therapy services and the use of communication aids. These facts are supported by previous studies that highlight the needs of vision, hearing aids and mobility as one of the issues that are most prevalent due to the existing technical challenges in authorizing these aids (Kenney & Kogan, 2013; Tan, 2015; Dusing et. al., 2004; Azman et al., 202; Islam et al., 2019).

The fact that children with learning disabilities, intellectual impairment and behavioural problems are more common than those who have other disabilities (Saloojee et. al., 2007; Zuckerman, 2014; Tan, 2015), make them more like to be denied therapy compared to other children with other disabilities (Saloojee et. al, 2007). Studies also demonstrated that children with autism are faced multiple issues in receiving healthcare services compare with other children with other functional disabilities (Zuckerman, 2014). It is said due to their disabilities not being physically visible and issues in communicating with them, it affects the healthcare services that they receive (Tan, 2015).

Studies also reported that healthcare providers have a reputation for poorly communicating and underestimating people with disabilities and their family cap abilities (Gibbs, Brown, & Muir, 2008). In the community, children with disabilities are commonly referred to their nearest CBR centres but studies reported those with severe disabilities were not being able to have their needs met due to lack of training by CBR workers (Kuno, 2007; UNICEF, 2014).

According to Tan (2015) in Malaysia, the prevalence of unmet needs for children with disabilities, is consider higher than most developed nation, but still comparatively low if compared to middle and low-income countries. This comparison however is limited at the international level due to the multiple definitions, and different measuring tools in capturing needs for children with disabilities.

Efforts done by the Philippines government to distribute therapists at health centres regardless of urban or rural area has been proven as a step in the right direction in making services for children with disabilities accessible (Lopez, Lewis, Boldy, 2000). Contrary to Malaysia, most specialized therapy and rehabilitation services are only based in urban town's hospitals which. Even though, effort in improving services in the

community has developed in Malaysia, accessibility is still an issue that needs to be addressed.

In recent time, current climate of the pandemic Covid-19, children of disabilities also suffered from an increased risk of mental health symptoms due the lack of social interaction which affected their morale and regressed their development. The lack of rehabilitation accessible during the Covid-19 lockdown causes severe concerns for the caregivers as they could not maintain or progress motor skills regularly and prevent complications that could further damaged their children progress in mobility and causes further physical deconditioning. Therefore, the interruption of the availability of medical care and rehabilitation could deteriorate the child's physical, mental and functional ability (Cacioppo et. al., 2021; Rashid et al., 2020).

Education

In Malaysia, studies have indicated that educators and teachers of children with disabilities lack the competency to efficiently educate children with disabilities (Ali, Mustapha, & Jelas, 2006). Despite concentrated efforts by Malaysian government to include children with disabilities in mainstream school, feedbacks from caregivers and children with disabilities have reflected that Malaysian current facilities and teaching capabilities are not able to support children with disabilities to study together with children without disabilities in the same facilities (Ali, Mustapha, & Jelas, 2006).

According to Sharma, Forlin, Deppeler, and Yang (2007), negative perception of children with disabilities and their families from incompetent teachers and educators have caused families to express their lack of confidence in educators and teachers in educating children with disabilities. In order to fully implement inclusive education, Malaysia needs to improve current facilities and infrastructures such as physical and support structures towards educator and teacher (Wah 2010). The upskilling and training of teachers and educators have to be prioritised in order to forged new perceptions towards children with disabilities disabled children and their families (Loreman, Forlin, & Sharma, 2007; Meijer, 2003; Norwich, 1994).

According to Jeste et al. (2020), the current pandemic of Covid-19 further complicates the issues as many children with disabilities lost access to education. Transitioning towards tele-education services have invoke concerns on the quality of education transmitted through the screens. This has further caused families of children with disabilities to complained that their children educational needs need major improvement, consideration and implementation to ensure the services

is at least on par with the typical face to face session that normally occurs before the pandemic.

Social Exclusion

According to Islam (2015), the context of Malaysian disabilities scenario also has constantly affiliated with social exclusion of children with disabilities. The perception of fear, ignorance and devaluation caused families with children with disabilities have the tendency to unnecessarily kept children with disabilities from being exposed to the current trends of the outside world. This deprived them of their recreational needs, including the need to play, interact and build relationships with the outside world.

The deprivation from these needs might disrupt children with disabilities' natural upbringing causes them to have a low quality of life. This restrict and limit their opportunities to learn how to be an independent and self-sustaining human being and denied them of the opportunity to build a close and dependent relationship with their family members (Lynch, Baker, & Lyon, 2009). Furthermore, families and caregivers especially female also experience stigma and social exclusion as the negative connotation towards children with disabilities and their affliction is still at large in Malaysia. The deep conflicts is the reason why in some families of children with disabilities, a paternal figure is not engaged in a caregiving role (Zuurmond et al., 2020)

Stigma and Discrimination

Children with disabilities and their families also faced stigma and discrimination from resulting in negative experiences from members of the public. The negative attitudes that children with disabilities received create barriers and denying the rights and dignity of the families of children with disabilities (UNICEF, 2013). Furthermore, according to UNICEF (2013) the stigmatisation and discrimination will cause further systemic isolation from their social, cultural and political opportunities that children with disabilities and their families are entitled to. This implicate and impact participation of children with disabilities and their families in their local community and cause them to be invisible and more vulnerable for exploitation.

Stigma can be defined as when an individual or their social group, face negative experience from the public (Read, Morton, & Ryan, 2015; Corrigan, 2000; Thornicroft, Diana, & Aliya, 2007). The definition is more or less the same in Asia, with the additional diverse socio-cultural context that needs to be accounted for in the population on how stigma works in the region (Yang, 2007; Ng, 1997; Singh et al., 2019; Ali et al., 2020). The damage from stigma and stereotyping, can deeply impact children with

disabilities confidence and self-assurance that can result in social isolation and reluctance to develop an engagement with the wider society (Lauber & Rössler, 2007).

One of the suggested ways to combat this and improve children with disabilities quality of life is by acknowledging children with disabilities and their families concerns by involving them in key decision-making process (ESCAP, 2000). The fact that children with disabilities and their families regardless of their capabilities were not included in decision making process is proof that systemic stigmatisation and discrimination occur in the wider society. This will further inflict low confidence and lack of aspirations on the future of children with disabilities which can contribute to them feeling self-stigma (Mont, 2014; WHO & World Bank, 2011; Department for International Development DFID, 2000). A study in Malaysia also indicates that individuals suffering from mental and intellectual disabilities also are more prone to suffer from self-stigma (Iqbal, Aun & Amin, 2017). This shows that children with disabilities particularly those with learning and intellectual disabilities are more prone to self-stigma compared to those with different disabilities.

The exclusion of families of children with disabilities in the existing economic empowerment programme shows that stigma and discrimination also existed in these type of services (Stienstra & Lee, 2019). This has been viewed as a failed opportunity to advocate the lives of children with disabilities. These type of support services should aim to combat stigma with the involvement of family members as a multi-faceted approach should they aim to be more successful.

Furthermore, stigma and discrimination towards children with disabilities will impact individuals and communities affiliated with them as well. Detailed studies into dissimilar forms of stigma in Asian countries shown that families play a vital role in the stigmatisation and discrimination process (Lauber & Rössler, 2007). Evidences suggest that families raising children with disabilities' quality of life were impacted heavily which highlighted (Shobana & Saravanan, 2014; Werner & Shulman, 2013; Lauber & Rossler, 2007). In Malaysia family members are also prone to be targeted to stigma and negative attitudes as shown in a study where mothers with children with disabilities were blamed and held accountable for giving birth to a disabled child (Mamba, 2010). This scenario is further supported by a study in East Malaysia that study quality of life of mothers with down syndrome children which shows stakeholders that were supposed to support them discriminate by choosing clients according to rural locality, race, and ethnicity (Geok, Khatijah, & Ling, 2013). This type of discrimination provoked a divisive

community which go against the vision to provide services in best interest of children with disabilities.

Stigma and discriminatory attitudes have also been proven to be correlated to the type of disability. A study in Peninsular Malaysia shows that mothers with autistic children were faced with less negative connotations compared to mothers with down syndrome (Geok, Khatijah, & Ling, 2013). On top of that, according to Lee et al. (2011), negative parental attitudes towards their own children with disabilities could also disrupt the children abilities and capabilities to be a functional and contributing member of society which can create unnecessary barriers to upskill children with disabilities into vocational training or formal employment (Lee, et al., 2011).

The Lack of Support Family in Caring for Children with Disability

Previous part of the paper demonstrated that family plays a fundamental role in the life of children with disabilities. However, studies have indicated that families of children with disabilities often received lack of or incompetent support services that impacted their emotional and socioeconomical well-being (Boyd, 2002; Ainbinder et al., 1998; Sloper & Turner, 1993). In Malaysia, lack of support due to the financial or geographical limitations is often the case as they had limited or no accessibility in accessing social services (Amin, Manap, & Akhir, 2016). Similar situation can be seen with children with intellectual disability who live with a range of challenges in mobility, communication and social functioning in managing their daily life which makes them highly dependent towards their caregivers to attend to these needs (Amin, Manap, & Akhir, 2016; Williams et.al, 2021).

Furthermore, according to Amin, Manap, and Akhir (2016), children with disabilities were given no choice but to choose to be facilitated into institutional settings and unable their families to care for them even if they are willing to. This scenario led to unwanted pressure and conflict as family caregivers were willing to sacrifice their time, energy, education, employment prospects and other resources to care for children with disabilities. This phenomenon has instigated a disruption in their family dynamics and caused disharmony which would later damage the social functioning of families with children with disabilities (Cuzzocrea, et. al., 2014; Kilic et al., 2013; Santamaria, et al., 2012;).

Structural Support

Some of the lack of support for families of children with disabilities are inadequate physical and structural support. As an example, in cases of children with disabilities where both parents are working a full-time job, the lack of disabled-friendly facilities or specialized day care centres, have

cause one of the parents to forgo their career to attend full time to their child's needs (Amin, Manap, & Akhir, 2016). More structural infrastructures such as disabled-friendly day-care centres and schools are needed to ensure the children with disabilities and their families can both be able to live their life to their upmost abilities.

The fact that majority of social support and services in Malaysia are only accessible in the urban area causes those in the rural area faced inaccessibility towards facilities and services that they were entitled to (Amin, Manap, & Akhir, 2016). In additional cases, basic information regarding related support services for families of children with disabilities was also not reachable for families in rural areas which is strange in this current aged of technological advancement. According to Paramjit et. al, (2020), varieties of issues and challenges arise involving families and caregivers' effort in trying to receive social support and services from the government and non-governmental agencies. Regardless, despite limitations and restrictions that they faced, most families with children with disabilities coped using benefit findings and optimism in overcoming these challenges (Slattery, McMahon, & Gallagher, 2017).

Psychological Support

On top of structural support, according to Amin, Manap, and Akhir (2016) psychological support for families with children with disabilities were lacking especially towards siblings and other family members who are directly or non-directly involved in caregiving for the children. The rationale of providing psychological support for other family members is that they might feel neglected as extra attention were normally given only to children with disabilities. This effort can succeed a series of psychological and counselling services by the government or non-governmental agencies. Apart from that efforts to build an open communication to be practised within the household children with disabilities is needed to reduce conflict and manage expectation between family members with and without disabilities (Cuzzocrea et. al., 2014). Head of household have to be adequately trained and prepared for of these situations to ensure these efforts are working.

Inadequate techniques and knowledge on disability also causes families with children with disabilities to have difficulties in coping when caregiving for children with disabilities (Sarvananthan, 2017; Halim et al., 2020). These challenges have caused families to feel burdened by caregiving and provoke tensions within family settings that impacted them psychologically (Tharshini, Ibrahim, Amin, & Zakaria 2016).

However, even though caregiving for children with disabilities causes distress among family members, studies have supported that families

showed positive coping experiences and benefited from their role as a caregiver (Hastings & Taunt, 2002). These approaches have resulted with higher quality of life for family members and their children (Brand, Barry, & Gallagher, 2014). Furthermore, focusing on these methods assist in combating depression and promote positive wellbeing (Cheng et. al., 2012) (Helgeson, Reynolds, & Tomich, 2006). Thus, these positive adaptative strategies have proven to be a crucial tool for family members and children with disabilities to cope with growing challenges in their caregiving roles (Slattery, McMahon, & Gallagher, 2017).

Conclusion

In conclusion, to combat varieties of issue and challenges, increased participation and interaction between people with disabilities and other local community has resulted in more positive experiences towards people with disabilities (Macmillan et al., 2014; Lee & Low, 2013). This can prevent discussed issues and challenges and lack of support from creating social isolation towards children with disabilities. Furthermore, involvement of government and non-govermental stakeholders can play larger role by increasing outreach programmes for families of children with disabilities who are facing inaccessibilities in obtaining available social services and support. Greater priorities has to be given to families with children with disabilities in the rural and low-income community to ensure that they are not left behind in receiving necessary needs and social services that are available in Malaysia. Thus, in developing a systemic process where families with children with disabilities regardless of background were able to access social support and services, Malaysia can move forwards toward improving the social well-being of familes of children with disabilities in Malaysia. In parallel with Malaysia's Person with Disabilities Act (2008), greater efficiency and active collaboration between agencies including Department of Social Welfare of Malaysia and the Ministry of Health of Malaysia can help overcome the unmet needs faced by children with disabilities and their families in Malaysia.

In a nutshell, it is important the needs for an increased social support and assistance for children with disabilities and their family member in Malaysia cannot ne more emphasized. As one of the country members that rectify the Conventions of the Right of Persons with Disabilities, Malaysia need to prioritize the prosperity of children with disabilities as their main priority in making sure social support and discussed issues and challenges are tackled. Furthermore, extra efforts into providing more accessibility of services and financial assistance especially for those in the low-income and rural locality in Malaysia. In achieving this, Malaysia can reduce negative implications on children with disabilities and their families from living their life to the fullest of their capabilities.

Acknowledgement

This work was supported by Universiti Sains Malaysia and the Malaysia Research University Network (MRUN) Translational Research Grant (USM-MTUN-MCUN) (304/PSOSIAL/656 209/K145).

Disclosure statement

No potential conflict of interest was reported by the authors.

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