

Understanding The Multifaceted Challenges Encountered by Foster Parents Caring for Children with Disabilities

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Abstract

Foster parents play a crucial role in the child welfare system by offering a family environment to nurture the children during their challenging period. Parenting is a challenging task under any circumstances, furthermore it is more challenging when for foster parents parenting a child with disabilities. Foster parents who care for children with disabilities have unique responsibilities that involve providing specialized care and support. Therefore, this study was conducted to explore the challenges faced by foster parents who care for children with disabilities. The study also intended to investigate the social support they needed to ensure that they are able to continue and maintain care for their children. This qualitative study used in-depth semi-structured interviews to gather the data among selected foster parents residing in the state of Selangor, Malaysia. The interviews were recorded and transcribed. Further, thematic analysis used to analyse the transcripts by using the Atlas.ti software version 9.0.5. Five themes emerge; full-time caregiver focus, high caregiving costs, lack of expertise in caring for a child with disabilities, education challenges for children with disabilities and foster children require various treatments. Findings could inform policy recommendations to better support foster families and enhance the well-being of children with disabilities.

Keywords: Foster Children with Disabilities, Foster Parents, The Challenge of Foster Parents, Social Support System, Qualitative Study.

Introduction

Understanding the multifaceted challenges faced by foster parents who are taking care for children with disabilities is under scrutiny in the Malaysian context. The importance of this study lies in the unique and complex needs of these children, and the caregivers who support

them. Foster parents play a key role in providing a nurturing and stable environment for children who have experienced trauma or neglect, and these responsibilities are further amplified when caring for a child with disabilities.

Studying the challenges encountered by foster parents in this specific context is essential for several reasons. Firstly, it sheds light on the experiences of a vulnerable population that may not always have their voices heard. By understanding the struggles, successes, and needs of foster parents caring for children with disabilities, we can work towards improving support systems and resources available to them. Furthermore, this area of study is crucial for enhancing the overall well-being and outcomes of both the children and the foster parents involved. By identifying and addressing the challenges faced by caregivers, we can ultimately create a more effective and inclusive foster care system that prioritizes the needs of these children and families.

The significance of studying the challenges faced by foster parents caring for children with disabilities lies in its potential to improve outcomes for children. Children with disabilities in foster care require specialized care and support. By exploring the challenges faced by foster parents in meeting these needs, we can ultimately improve the well-being, development, and quality of life of these vulnerable children. Foster parents are essential in providing a loving and stable home for children in need. Understanding the challenges they encounter when caring for children with disabilities is crucial in order to provide them with the necessary support, resources, and training to fulfil their caregiving roles effectively. Therefore, by gaining insights into the experiences of foster parents caring for children with disabilities, we can work towards creating a more inclusive and responsive foster care system. This can help ensure that all children, regardless of their abilities, receive the care and support they need to thrive.

Empowering foster parents with knowledge and resources to effectively care for children with disabilities is beneficial not only for the children but also for the caregivers themselves. It can increase their confidence, reduce feelings of isolation, and ultimately lead to more positive caregiving experiences. In essence, the significance of studying the challenges faced by foster parents caring for children with disabilities lies in its potential to improve outcomes for children, enhance support for caregivers, inform policy and practice, strengthen the foster care system, and empower those involved in the care of these vulnerable populations.

A child's disability status could affect their experience in foster care. Other possibly influencing factors include the type of environment they're placed in, and the duration before it takes to find a permanent placement. Commonly, foster families are expected to provide the complex needs of children with disabilities either physically or emotionally. Despite these studies, there remains limited understanding of the precise extent to which disabilities influence long-term outcomes. Factors such as resilience, support networks, and individual variations play a role (Bruskas, 2008; Gyphen et al., 2017; Slayter, 2016).

Foster care is a system in which children who cannot live with their biological parents due to various reasons (such as abuse, neglect, or parental incapacity) are placed in the care of other families or institutions. The brain undergoes significant development during early childhood, especially in the first few years of life. This period is crucial for cognitive, emotional, and physical growth. Some children entering foster care have complex health issues (physical or mental) or developmental challenges. These could include chronic illnesses, disabilities, trauma, or behavioral disorders. The American Academy of Paediatrics

(AAP) emphasizes that children with complicated health or developmental issues are particularly vulnerable during the early years. Foster families, caregivers and professionals need to be aware of the unique needs of these children. It is important to recognize the vulnerability of children with health or developmental complexities during their early years, especially when they enter foster care.

While fostering any child comes with challenges, caring for disabled foster children introduces additional complexities related to healthcare, education, finances, and emotional well-being (Finardi et al., 2022). The resilience, dedication, and advocacy skills of foster parents play a crucial role in addressing these challenges and providing a supportive and nurturing environment for children with disabilities in foster care. The need for specialized support services, ongoing training, and a robust support network becomes essential for foster parents undertaking the unique responsibilities associated with caring for disabled foster children.

The Malaysian government has taken initiatives to improve the lives of persons with disabilities (PWDs) in Malaysia, such as the establishment of special schools and the enactment of the Persons with Disabilities Act 2008. These efforts demonstrate Malaysia's commitment to helping parents and caregivers of children with disabilities and ensuring equal treatment for PWDs. However, in the Malaysian context, to date, the issues and challenges among foster parents are under scrutiny, let alone foster parents with disabled children. Therefore, this study intended to explore the experiences of foster parents who care for children with disabilities in Malaysia. By understanding their challenges, we can work toward a more inclusive and supportive foster care system.

In conclusion, delving into the multifaceted challenges encountered by foster parents caring for children with disabilities is not only important but necessary for ensuring the holistic care and support of this vulnerable population. This research can help inform policies, practices, and interventions that aim to enhance the lives of children with disabilities in foster care, as well as the well-being of their caregivers.

Literature Review

Foster parents caring for children with disabilities face various challenges. These challenges include high levels of stress Manisah (2023), lack of supportive social networks, overwhelming caretaking responsibilities Sharifa, et.al (2022), fatigue managing children's daily routine Ethar et. al (2022), children's health problems Theresa & Antwi (2023), discrimination, physical exhaustion, and a lack of time to seek lucrative work options. Additionally, foster parents may experience financial difficulties, loneliness, and a lack of outside support. Coping with these challenges can be difficult, but foster parents may utilize various strategies such as reframing and mobilizing family to acquire and accept help from others. Family support, social support from churches, and spirituality are also important coping mechanisms for foster parents. It is crucial for foster parents to receive support and assistance from government and non-governmental organizations to strengthen their parenting skills and effectively manage the challenges they face.

Addressing these challenges requires a holistic approach, involving improved training, increased support networks, and better collaboration between foster parents, professionals, and agencies involved in the care of children with disabilities within the foster care system. Here are some common problems faced by foster parents in such situations:

i. Limited Training and Resources

Foster parents may not receive adequate training or resources to address the specific needs of children with disabilities. This lack of preparation can lead to frustration and difficulty in providing appropriate care.

ii. Specialized Care Requirements

Children with disabilities often require specialized care, such as medical treatments, therapy sessions, or assistive devices. Foster parents may face challenges in managing and fulfilling these unique caregiving responsibilities

iii. Educational Challenges

Navigating the educational system for a child with disabilities can be complex. Foster parents may need to advocate for the child's educational needs, work closely with special education professionals, and ensure the child receives the necessary support in school

iv. Emotional and Behavioral Issues

Children with disabilities may experience emotional and behavioral challenges, and foster parents may not always have the necessary tools to manage these issues effectively. Understanding the root causes of certain behaviors and implementing appropriate strategies can be demanding

v. Advocacy Struggles

Advocating for the rights and well-being of a child with disabilities within the foster care system and in other settings can be challenging. Foster parents may encounter resistance or lack of awareness from various agencies and professionals

vi. Limited Respite Care

Foster parents of children with disabilities may have limited access to respite care services. The demanding nature of caregiving for a child with special needs can lead to burnout, making respite care crucial for the overall well-being of the foster family

vii. Social Isolation

Caring for a child with disabilities can be isolating, as some families may face challenges in finding inclusive social activities or experiencing societal stigma. Foster parents may feel isolated from their peers who may not fully understand the complexities of their situation

viii. Uncertain Future Planning

Planning for the long-term future of a child with disabilities, including potential transitions to adulthood, independent living, or ongoing care, can be daunting for foster parents. Navigating legal and financial considerations becomes more complex in these cases.

x. Lack of Support Networks

Foster parents may struggle to find support networks that understand the unique challenges they face. Connecting with other foster parents of children with disabilities or accessing specialized support groups can be essential for sharing experiences and coping strategies.

xi. Inadequate Collaboration with Professionals

Foster parents may encounter challenges in collaborating with healthcare professionals, therapists, and educators. Effective communication and coordination are crucial for providing comprehensive care for children with disabilities.

Crucial aspect to ensuring the success of foster care for disabled children

The use of "crucial aspect" underscores that this exploration is not optional but fundamental to ensuring the success of foster care for disabled children. Ignoring the emotional and psychological resilience of foster parents may lead to burnout, decreased effectiveness in caregiving, and potential negative outcomes for both the parents and the children.

1. Financial Strain in Specialized Care

The financial aspect of foster parenting, particularly when caring for children with disabilities, involves a multitude of added complexities. Understanding these added complexities sheds light on the financial challenges faced by foster parents caring for children with disabilities. It emphasizes the need for targeted support, awareness, and policy considerations to ensure the well-being of both foster parents and the children under their care.

i. Medical expenses

Children with disabilities often require specialized medical care, including frequent doctor visits, medications, therapies, and medical equipment. Foster parents may face increased medical expenses compared to those caring for children without disabilities. The costs can encompass prescription medications, assistive devices, and therapies not always covered by insurance.

ii. Therapy cost

Children with disabilities frequently require various therapies such as physical therapy, occupational therapy, speech therapy, and behavioral therapy. These therapies can be expensive and may not be fully covered by insurance. Foster parents might need to navigate complex healthcare systems to ensure their foster child receives the necessary therapeutic interventions.

iii. Educational expenses

Educational support for children with disabilities may involve additional costs for specialized tutors, educational materials, and assistive technology. Foster parents may encounter challenges in accessing appropriate educational resources and may need to invest in supplemental materials and services to support their foster child's learning needs.

iv. Adaptive equipment and technology

Many children with disabilities require adaptive equipment and technology to enhance their daily lives and facilitate independence. Acquiring specialized equipment such as wheelchairs, communication devices, or sensory aids can incur significant costs. Foster parents may need to navigate funding sources or seek community support to obtain these essential tools.

v. **Impact on employment**

Caring for a child with disabilities may necessitate adjustments in the foster parent's employment situation, potentially affecting income. Balancing work commitments with the demands of caring for a child with disabilities may result in reduced working hours, missed career opportunities, or the need to take unpaid leave, further impacting the family's financial stability.

vi. **Unexpected cost**

Children with disabilities may encounter unforeseen health-related events or emergencies, leading to additional costs. Foster parents may need to manage unpredictable expenses associated with medical crises or unforeseen needs, creating financial stress and uncertainty.

vii. **Navigating support systems**

While there are support systems in place, navigating them can be challenging and time-consuming. Foster parents may struggle to access available financial assistance, grants, or support programs due to bureaucratic hurdles, lack of awareness, or limited availability of resources.

viii. **Long-term financial planning**

Planning for the long-term financial needs of a child with disabilities, such as transition to adulthood, independent living, or ongoing healthcare costs, adds an extra layer of complexity. Foster parents may need to consider the financial implications of their foster child's disability throughout their life, requiring careful financial planning and potentially impacting retirement plans.

2. Educational Navigations

Challenges related to education, such as advocating for inclusive education, navigating Individualized Education Programs (IEPs), and addressing barriers to educational attainment for children with disabilities in foster care. Understanding these challenges helps shed light on the intricate nature of advocating for the educational needs of children with disabilities in foster care. Foster parents play a crucial role in navigating these complexities, emphasizing the importance of collaboration, advocacy, and a deep understanding of both the educational and foster care systems.

i. **Advocating for inclusive education**

Inclusive education involves creating environments where all students, including those with disabilities, can actively participate and learn. Foster parents may encounter resistance or lack of understanding from school administrators or educators regarding the benefits of inclusive education. Ensuring that the foster child is fully integrated into the mainstream classroom may require ongoing advocacy efforts, collaboration with school staff, and addressing potential biases or stereotypes.

ii. **Navigating individualized education programs (IEPs)**

IEPs are customized plans designed to meet the unique needs of students with disabilities, outlining specific educational goals and support services. Foster parents may face challenges in navigating the IEP process, which can be complex and

overwhelming. Ensuring the IEP accurately reflects the foster child's needs, collaborating with school personnel, and attending IEP meetings may be time-consuming and emotionally taxing for foster parents.

iii. Addressing barriers to educational attainment

Children with disabilities in foster care may encounter various barriers that hinder their educational progress. Foster children may experience disruptions in their education due to frequent placement changes, impacting their continuity of learning. Transferring records, ensuring consistent educational support, and addressing gaps in academic achievement may be challenging for foster parents as they navigate the child welfare and educational systems.

iv. Ensuring accessibility and accommodations

Accessibility refers to creating environments and materials that everyone, including those with disabilities, can access and use. Accommodations are adjustments made to support individuals with disabilities in their learning. Foster parents may encounter difficulties in ensuring that the educational environment is physically accessible and that appropriate accommodations are in place to meet the foster child's specific needs. Advocating for necessary accommodations, such as assistive technology, modified assignments, or accessible facilities, can be a continuous process.

v. Collaborating with educational professionals

Collaboration between foster parents and educational professionals is essential for the success of a child with disabilities in the school setting. Foster parents may face communication barriers or encounter resistance from educators who may not fully understand the unique circumstances of foster care. Building effective partnerships with teachers, school administrators, and special education staff requires ongoing effort and commitment to advocate for the foster child's educational needs.

vi. Transition planning

Planning for transitions, such as moving between grade levels or preparing for post-secondary education, is critical for children with disabilities. Foster parents may face challenges in ensuring smooth transitions for their foster child, including coordinating services, communicating with relevant professionals, and addressing potential disruptions in learning during transitions.

3. Healthcare Access and Advocacy for Special Needs

The healthcare challenges for children with disabilities are multifaceted, encompassing issues of accessibility, awareness, and financial constraints. Foster parents play a pivotal role in advocating for their foster children, addressing these challenges, and ensuring that the healthcare system meets the unique needs of each child with a disability. Their commitment to the health and well-being of these children contributes significantly to their overall development and quality of life

i. Limited accessibility to specialized services

Children with disabilities often encounter barriers when trying to access specialized healthcare services tailored to their unique needs. Geographic location, economic

disparities, and inadequate infrastructure can limit their ability to reach specialized facilities.

ii. Lack of awareness and understanding

Healthcare providers may not always have sufficient knowledge or training to understand and address the specific needs of children with disabilities. This lack of awareness can result in misdiagnosis, inappropriate treatments, or a failure to provide comprehensive care.

iii. Financial constraints

Families with children with disabilities may face financial challenges due to the costs associated with specialized treatments, assistive devices, and therapies. Affordability can be a significant barrier to accessing necessary healthcare services.

iv. Fragmented healthcare system

The healthcare system may be fragmented, with poor coordination between different providers and services, making it difficult for families to navigate and access comprehensive care.

Social support needed by foster parents

Foster parents taking care of children with disabilities require social support to ensure their well-being and the well-being of the children. The social support needs of these caregivers include emotional support, information support, access to services, financial and economic support, and support for early diagnosis and intervention (Syukriah, 2022; Akeem, 2022). Caregivers also benefit from support in terms of discrimination, medical problems, and psychological issues (Maryna, 2020). Social support has been found to have a positive impact on the psychosocial adjustment of children with disabilities, including increased self-esteem, positive behavioral adjustment, and improved mental health (Syakila, 2020). The availability and quality of social support differ between countries, with Indian caregivers reporting greater availability of helpful support compared to South African caregivers (Kruglova, 2022). Overall, social support plays a crucial role in helping foster parents effectively care for children with disabilities and improve their overall well-being.

Methodology

This article is based on the bigger study that involved selected foster parents residing in the state of Selangor, Malaysia. This qualitative research employed in-depth interview methods by using semi-structured questions. The interview protocol was based on a literature review and adapted from (Asmussen and Creswell, 1995). During the interviews, the researcher presented open-ended questions to the informants, and subsequent questions were based on the answers provided by the informants. The main researcher also used probing techniques to extract clearer information from the statements given by the informants.

According to statistics by the Social Welfare Department of Malaysia, the state of Selangor has the highest statistics for the placement of children in foster care. In 2023, a total of 228 cases of foster children were placed in the care of foster parents in Selangor and this is the highest case in Malaysia. A total of five individuals consisting of foster mothers and fathers were chosen as study informants using purposive sampling techniques. The characteristics of these informants are as follows: (i) foster parents who have been granted

custody rights by the Director-General of Social Welfare (KPKM) to care for children under Section 30(1)(e) of the Child Act 2001, (ii) foster parents who have been granted custody rights by the Court for children under Section 30(1)(b) of the Child Act 2001, i.e., placement of children under the care of a qualified and suitable person, (iii) foster parents with at least two years of experience in caring for foster children. The informants were also referred by child protection officers from the District Social Welfare Office (PKMD) in Klang, Subang Jaya, Petaling Jaya, Hulu Langat, and Gombak, responsible for handling foster care cases.

The data obtained were then analyzed using thematic analysis (Braun & Clarke, 2006) with the assistance of the Atlas.ti software.

Research Finding and Discussion

Table 1

Socio-demographic characteristics of the informants

Nick name of foster parent	Sex / Age	Occupation	Age of the foster child	Type of disability
Zaid	Male / 53 years	Jobless / illness / Pension SOCSO	14 years	Physical Disability (Epilepsy)
Ina	Female / 55 years	Housewife	14 years	Physical Disability (Epilepsy)
Maznah	Female / 52 years	Housewife	17 years	Physical Disability
Ahmad	Male / 55 years	Contractor	3 years	Physical Disability (Cerebral Palsy)
Fatimah	Female / 56 years	Housewife	3 years	Physical Disability (Cerebral Palsy)

Table 1 shows socio-demographic characteristics of five (5) informants participated in the study. From five informants; two of them were the foster fathers and three of them were the foster mothers. All of them are aged above 50. All of the foster mothers were housewives and one foster father was working as a contractor. Whilst one foster father was receiving a monthly pension from the Social Security Organization (SOCSO) due to some illness, he lost his permanent ability. Three of the foster children were teenagers (14 and 17 years) and two of them were toddlers (3 years). All of the children were having physical disabilities with two of them having epilepsy and two of them were having cerebral palsy.

The challenges of foster parents to care for disabled foster children

Foster parents caring for children with disabilities face challenges due to the demanding role caused by the complex needs of these children (Puddy & Jackson, 2003; Goetting & Goetting, 1993). This is attributed to the behavioral challenges of children with disabilities and the challenges related to the attachment between the child and the foster family (Tarren-Sweeney 2007; Brown & Rodger, 2008). Moreover, the financial costs of caring for children with disabilities are higher than those of raising non-disabled children (Reilly & Platz, 2004; Brown & Rodger, 2008). These high costs are incurred due to the needs of children with

disabilities, which may require specialized medical, educational, or psychological services (Reilly & Platz, 2003; Vig & Kaminer, 2002). Here are the challenges faced by foster parents based on the results of the study:

i. Full-time caregiver focus

In the care of foster children with disabilities, foster parents face challenges in providing full-time care. According to Zaid, they gave up their career to take care of their foster child who has Epilepsy and requires special care and recovery programs. The decision to quit from the job was uneasy, but they prioritized the needs of their foster child with disabilities. Additionally, their sibling, who had been assisting in caring for the foster child while they were working, is no longer able to take care of the child. She quoted as; "Now I don't work anymore, my sibling is old and can't manage to care for the child, so I had to quit [my job]."

According to Maznah, they have to provide full-time care for their foster child because the child cannot speak and is incapable of taking care of themselves. The child's condition, which requires reliance on the assistance of others, poses challenges for the foster parents. Maznah explains,

"We are taking care of everything ourselves... Yes, we do it. He can take a shower, but only pour water on himself. Like that. We have to clean up everything, from urine to bowel movements... He hasn't been able to do it on his own from the beginning until now. But in the doctor's letter, it says he depends on our assistance for his livelihood."

The statement highlights the significant caregiving responsibilities and the child's dependency on the foster parents for daily activities.

Fatimah, on the other hand, feels that it is time for their foster child to receive full-time care from the foster family. This decision stems from their concerns about the daycare center (TASKA), which they fear may not provide the best possible care for their foster child. They had to sacrifice their career as a professional architect because they believed it was time to give their full attention to their foster child with Cerebral Palsy. According to them;

"There's nothing... Anyway, I feel that at her age now, she needs a lot of interaction with her mother and father, or whatever. So if we leave her at a nursery or babysitter, what can they really teach her? I mean, even the nursery. The nursery can't accept a three-year-old child nowadays, you know. So..."

This statement reflects the informant's decision to prioritize the foster child's need for personalized attention and interaction over external care services like daycare or babysitters.

ii. High Caregiving Costs

In addition to the need for full-time care for foster children with disabilities, the high costs of caregiving pose a significant challenge for foster parents caring for children with disabilities. Children with disabilities have unique needs such as disposable diapers, specialized formula, and specific foods. These expenses result in the foster parents not being able to meet the specific needs of children with disabilities. According to Zaid, they cannot afford to purchase nutrient-rich and expensive food items as recommended by the doctor for their foster child. The statement highlights the financial constraints on foster parents, making

it difficult for them to provide the specialized care and nutrition required for children with disabilities due to the high cost of the items.

"In dealing with his diapers and formula, it's not like ours. He has to eat a soft diet. I don't know, I don't count... Two bags of diapers a month... The doctor did recommend using special diapers, but I can only afford regular Dutch Lady milk... The doctor did say he needs to eat those things with certain nutrients, but I can't afford it... Before, even when he was little, he wanted something tasty like soy milk..."

Zaid is expressing the financial challenges in meeting the specific needs of their foster child with disabilities. The child requires special diapers and a specific type of formula, but due to financial constraints, the foster parent can only afford regular items. The statement reflects the difficulty in providing the recommended nutrition and care for the child with disabilities, illustrating the financial limitations that impact their ability to meet the child's unique requirements as advised by the doctor.

iii. Lack of expertise in caring for a child with disabilities

In addition, foster parents also face challenges in managing children with disabilities because they lack specific skills. They also encounter difficulties in finding caregivers who are capable and qualified to handle the foster child with disabilities. According to Zaid, nobody knows how to take care of their foster child because the child requires lifelong assistance. Here is the statement, "With his sibling being in this condition. People don't know how to feed, don't know how to give water [to drink]... anything. Drinking, eating, bathing, they don't know anything. Nobody knows.."

Zaid, is highlighting the struggle of foster parents who lack the specialized knowledge and skills required for taking care of a child with disabilities. The statement emphasizes the challenges in finding suitable caregivers who understand the unique needs and demands of the foster child with disabilities. The foster parent expresses the frustration of dealing with the lifelong care requirements of their child and the limited understanding and assistance available from others. The researcher also got the views from the other foster father, Hariz, about the care of disabled foster children. He quotes as such :

"I don't think he... honestly, someone with expertise knows how challenging it is to take care of them. So, he won't do it. Someone with expertise can estimate how much money I have to spend in a year to take care of a special needs child, whether it's autism or whatever. We know how difficult the commitment is, limited movements, you have to give attention 24 hours. It's just not possible for him..."

Hariz is expressing gratitude for only caring for a normal foster child while acknowledging the challenges faced by foster parents caring for children with disabilities. He highlights the perspective that individuals with expertise in special needs care understand the intricacies and difficulties involved. The informant suggests that someone with such expertise would be aware of the financial commitments and the constant attention required for the care of a child with special needs, emphasizing the demanding nature of the commitment and the limitations in terms of time and attention.

iv. Education challenges for children with disabilities

In caring for children with disabilities, foster parents also face difficulties in finding suitable educational placements for these children. According to Maznah, limited educational opportunities and a lack of disability-friendly facilities force them to seek appropriate places for children with disabilities, such as Community-Based Rehabilitation Centers (Pusat Pemulihan Dalam Komuniti). Here is their statement:

"She entered secondary school for a year. After that, Kak maznah said, 'Why bother with academics, that's academics.' Then Kak Maznah transferred him back to the PDK. Because the teacher said now it's not possible, they only take them at 15. So, when she turned 15, Kak Maznah transferred him here.."

Maznah is highlighting the educational challenges faced by foster parents in finding suitable and inclusive educational settings for children with disabilities. The statement emphasizes the limited academic options and the need to explore alternative educational environments, such as the Rehabilitation programs in the community (PDK), due to the constraints and limitations of the mainstream educational system in accommodating the unique needs of children with disabilities

V. Foster children require various treatments

The foster parents caring for a child with disabilities face challenges in managing the child's illness, which requires various treatments and therapies. Ahmad and Fatimah, who are a foster parent couple, care for a foster child with Cerebral Palsy, necessitating diverse treatments and therapies for the child's recovery program. Among the therapies their foster child undergoes are Occupational Therapy, Speech Therapy, Radiotherapy, and Physiotherapy. Consequently, the foster parents must make significant sacrifices in terms of time and financial resources to ensure their foster child receives the appropriate therapeutic interventions

This statement underscores the complexity and intensity of the care involved in raising a child with disabilities, particularly one with Cerebral Palsy. The mention of multiple therapies highlights the comprehensive approach needed to address various aspects of the child's condition. The reference to sacrifices in time and financial resources emphasizes the dedication required from foster parents to provide the necessary care and support for the foster child's well-being and development

The statement provided by Ahmad and Fatimah details the various treatments and therapies their foster child with Cerebral Palsy undergoes:

1. **Physiotherapy:** The foster child receives physiotherapy, involving stretching exercises and activities in a water pool. This therapy is conducted on a weekly basis
2. **Occupational Therapy:** Occupational therapy is administered once a month. This therapy focuses on developing the child's skills and abilities for daily activities, considering the challenges posed by their condition
3. **Speech Therapy:** The foster parents initially express concern about the child's speech development, as there was a delay in the child starting to vocalize. However, after two years, the child began making sounds. Speech therapy is not explicitly mentioned as a regular occurrence, but its importance is highlighted in the context of the child's delayed speech development

4. Radiotherapy: Radiotherapy is conducted every two weeks. It's important to note that radiotherapy typically refers to a medical treatment using radiation for certain conditions, but the context here might suggest a different kind of therapeutic approach or a terminology confusion

The foster child participates in classes with three or four other children, some of whom may also have Cerebral Palsy or other mobility challenges. The sessions are structured based on age groups, and the range of costs is mentioned, indicating the financial commitment required. The frequency and duration of each therapy session are also specified, illustrating the intensive nature of the foster child's treatment plan. Overall, the statement provides insight into the comprehensive and ongoing therapeutic interventions necessary for the child's well-being and development

The situation becomes even more challenging and burdensome for foster parents because their foster child with disabilities does not have citizenship status. This is experienced by Ahmad and Fatimah, who also face challenges in obtaining citizenship for the child. They highlight that if the foster child does not have citizenship status, they automatically cannot access the OKU card (a card for persons with disabilities) and assistance from the Department of Social Welfare (JKM). Similarly, access to medical treatment in hospitals becomes limited, and they are forced to incur high costs to obtain medical care for their foster child. This extremely challenging situation adds further difficulties to the lives of foster parents. The following statement from Ahmad and Fatimah provides more insight into this issue

"Birth certificate is crucial, then citizenship is expedited... Another thing, because she has OKU status. That's why we applied for OKU status, but we didn't get it... But OKU status must be for Malaysian citizens, it can't be for non-citizens... Citizenship plays a big role because if she is not Malaysian, of course, the government doesn't want to take responsibility"

Ahmad and Fatimah underscore the significance of citizenship status, not just for legal documentation but also for accessing crucial support systems and services for their foster child with disabilities. The mention of the OKU card, government assistance, and medical treatment highlights the intertwined challenges foster parents face when their foster child does not have citizenship status.

In addition, foster parents face challenges when their non-citizen foster child does not receive exemptions from medical treatment costs. Therefore, foster parents need to allocate additional funding to cover these treatment expenses. According to Zarina, they have to obtain a support letter from the Department of Social Welfare (JKM) to qualify for exemptions from hospital treatment costs. Here is their statement:

"Before this, I asked for Ms. Nurul's assistance to obtain an exemption letter... because this child does not have citizenship yet... We just got the birth certificate done... Ms. Nurul handled it... the birth certificate is now available, but it states non-citizen... so, for the hospital, I usually use the letter from JKM... but for clinics, we usually just pay... Some clinics are okay, no problem... sometimes they check where the child's identification document is because they see the mother has an identification document... but the child, I tell them he's an adopted child... but some clinics are okay, they don't charge... but some clinics, sometimes because they follow procedures, they charge... for hospitals, I only use that letter... but

that's the last option... now it's not possible anymore... because now... I've... the court case is over... I have the adoption certificate... so it's my responsibility... I just don't know... because I work in the government.”

Zarina details the complexities faced when a foster child is not a citizen, particularly in relation to medical treatment costs. The process involves obtaining support from JKM, utilizing specific documentation, and navigating different procedures at clinics and hospitals. The statement also alludes to the foster parent's uncertainty about the child's status, given their employment in the government sector. This illustrates the multifaceted challenges and bureaucratic hurdles foster parents encounter when seeking exemptions for medical costs for their non-citizen foster child.

In addition, the high treatment costs must be covered by foster parents themselves because the foster child is not a citizen. According to Zarina, they had to borrow money from a friend to pay the treatment costs amounting to RM 2000. Here is their statement:

"Aha, I paid the treatment cost of RM 2000 myself... I: Yes.. because like me.. I borrowed money from a friend.. everything.. Where can I get RM 2000 at that time... After that, I borrowed from a friend.. if someone else.. we don't know if someone else gets a sick child.. later, if people find out.. they wouldn't want to take a sick child.. because if you take a sick child.. you go to the hospital.. if there's no citizenship status, we have to bear the cost.. have to go through the process.. I keep remembering things like not knowing who to express it to.. because I remember children who later also.. so we hear more about adopted children.. these abandoned children.. Who will take care of the sick ones? If a family that is not financially capable gets them, it's okay.. if a family that is capable gets them.. it's just a different commitment.. I say eventually, there won't be anyone willing to take in sick children.. cases like this.. sad.. I'm sad.. when I brought [the child] to Serdang, Serdang refused to consider at all”

Zarina reveals the financial strain faced by foster parents due to the high costs of medical treatment for a non-citizen foster child. They highlight the difficulty in securing financial assistance and the emotional burden associated with caring for a sick child without citizenship status. The statement emphasizes the challenges of finding willing families to care for sick children, especially when financial considerations and bureaucratic processes become significant obstacles.

Without adequate experience, training, and resources required to care for the unique medical and educational needs of a child with disabilities, a foster family may feel unprepared for and stressed by unexpected challenges, such as medication management, healthcare navigation, and participation in special education programs (Brown & Rodger, 2009). These events could result in a placement disruption, moving the child to another foster home and further compounding the child's vulnerability.

However, there were four differences which suggest areas worthy of additional research, including the monetary costs associated with fostering a child with a disability, the role of the community – social networks, and physical neighbourhood characteristics – in the care of foster children with disabilities, the circle of care of children with disabilities, as well as the particular needs and challenges of foster parents who themselves have disabilities. The financial needs of foster parents have been explored in the literature in relation to recruitment and retention and whether increased stipends make a difference.

The foster parents in this study did not suggest that a simple relationship exists between their ability to care for a child and the financial support they receive. Indeed, the costs of caring for a child with a disability that necessitates substantial up-front expenses – such as structural changes to a home, particular pieces of equipment for mobility, communication or learning – are not consistent across children or foster parents. The realities that parents describe are unique and specific to a particular child in a particular context, and the support costs (for the children, not the foster parents) should be determined on the basis of those factors. The calculation formula employed to determine eligibility for financial support did not fit well with the special circumstances and real out-of-pocket costs borne by foster parents in the study. It may be worthwhile to explore the real costs, from the perspectives of foster parents, as well as potential funding methods for foster families with children who have disabilities that are commensurate with their realities.

Conclusion

The success of the fostering system for foster parents with disabilities caring for foster children with disabilities hinges on the government's commitment to inclusivity, accessibility, and support. By implementing policies and initiatives that address the unique needs of this demographic, the government contributes to creating an environment where foster parents with disabilities can provide effective and nurturing care to children with disabilities. This, in turn, leads to positive outcomes for both foster parents and the children they are caring for within the fostering system.

The Role of Foster Parents in Advocacy

Foster parents play a crucial role in understanding the specific healthcare needs of their foster children with disabilities. Their close relationship allows them to identify health concerns, track progress, and communicate effectively with healthcare providers. Foster parents can provide valuable insights and education to healthcare providers about the child's history, preferences, and responses to different treatments. This collaborative approach enhances the quality of care and fosters a better understanding of the child's unique needs.

Foster parents often act as advocates and navigators within the healthcare system, helping to bridge gaps and ensuring that their foster children receive timely and appropriate care. They may coordinate appointments, communicate with various healthcare professionals, and ensure continuity of care. In addition to physical health, foster parents advocate for the emotional and social well-being of their foster children, recognizing the interconnected nature of health. They work to create a supportive environment that promotes the child's overall development. Foster parents also need to collaborate with support services, such as special education programs, therapists, and community organizations, to ensure a holistic approach to the child's well-being.

The Role of Government

The government plays a crucial role in supporting the success of the fostering system within a community, particularly when focusing on foster parents with disabilities caring for foster children with disabilities. Government can contribute to ensure that resources of the fostering system through training materials and support services are accessible to foster parents with disabilities. This includes providing information in various formats and accommodating different learning styles. Foster parents with disabilities should receive

reasonable accommodations to participate fully in training programs, support groups, and other aspects of the fostering system.

In addition, developing training programs will benefit if they specifically address the unique needs and challenges faced by foster parents with disabilities. This includes training on adaptive parenting techniques, accessible home environments and effective communication strategies. Training providers must ensure that training environments are physically accessible, and training materials are available in accessible formats to accommodate diverse abilities.

The government must provide financial support that takes into account the additional expenses associated with caring for a child with disabilities. This may include funding for assistive devices, specialized therapies, and other disability-related needs. Allocate resources to support foster parents with disabilities in accessing necessary assistive technology, accessible transportation, and other resources that facilitate effective caregiving. Providing legal support services is also crucial for foster parents. Foster parents with disabilities may face unique challenges during legal proceedings, especially when advocating for the rights of the child. Accessible legal assistance can empower them to navigate complex situations effectively.

Launching anti-stigma campaigns should be a priority to raise awareness and reduce societal misconceptions about disabilities. By actively promoting understanding and empathy, the government can play a pivotal role in shaping public attitudes towards individuals with disabilities. In parallel, the government should champion community engagement programs that encourage collaboration and mutual support among foster families. These initiatives can create a supportive environment, breaking down barriers and fostering inclusivity. By actively promoting and facilitating community involvement, the government can help build a foundation for a more compassionate and understanding society.

Another essential aspect of the government's responsibility is the establishment of peer support programs. Connecting foster parents caring for foster children with disabilities through these initiatives allows them to share experiences, insights, and practical advice. This peer-to-peer support network can be a valuable resource, providing emotional support and practical guidance to foster parents facing similar challenges.

In summary, supporting foster parents with disabilities requires a multifaceted approach. By strengthening legal protections, launching anti-stigma campaigns, fostering community engagement, providing peer support, and investing in research, governments can create a more inclusive and supportive foster care system. Community must work together to ensure that every foster parent, regardless of their abilities, receives the necessary resources and understanding to provide loving care for children in need.

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